"What does it mean to me?": A Q-methodological exploration of the beliefs held about Asperger's Syndrome/High Functioning Autism when the diagnosis is received in adulthood.

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ABSTRACT

Introduction: This study aims to explore the ways in which Asperger's Syndrome and High Functioning Autism are understood by those who have received a diagnosis in adulthood. The experience and understanding of diagnosis in adulthood has been little researched with only a small number of qualitative studies having been completed (Cousins, 2001; Molloy & Vasil, 2004; Punshon, 2006). These studies all highlight the importance of the beliefs held about Asperger's Syndrome on the experience of diagnosis and post-diagnostic identity development. Due to the increasing awareness and diagnosis of Asperger's Syndrome in adulthood, research into how the diagnosis is understood is invaluable for clinicians supporting individuals through the process.

Method: This study uses a Q-methodology (Stephenson, 1953) to build upon recent qualitative research. The methodology is based on two techniques, the Q-sorting process and Q-factor analysis. For the Q-sorting process a set of 52 statements were developed which attempted to provide coverage of the understanding of Asperger's Syndrome currently in the public domain. A wide range of sources were used to develop the Q-set, including a focus group with six adults with Asperger's Syndrome. Eighteen individuals who had received their diagnosis in adulthood were recruited to complete the Q-sorting process, which involved them having to rank the statements based upon their agreement with them. Additionally a semi-structured interview was completed to gather information regarding the sort and supplementary demographic information.

Results: Q-factor analysis involving principal components analysis and varimax rotation was then carried out. This led to four statistically significant and theoretically meaningful factors being extracted. The four factors were interpreted using the additional information gathered, and were labelled *'An important part of me'*, *'It is a lifelong disability'*, '*Confused about myself*, and '*Support can bring improvement'*.

Discussion: The findings were discussed with consideration of the clinical implications and scope for further research. Particular emphasis was placed on discussing three main areas 'acceptance and adjustment', 'consequences of diagnosis' and 'theoretical conceptualisations'. The importance of further research into the links between understanding and mental health were highlighted.

INTRODUCTION SECTION.

This study is focussed on exploring the experience of the diagnosis of Asperger's Syndrome and High Functioning Autism in adulthood. Chapter 1 outlines the current understanding of Asperger's Syndrome and High Functioning Autism by the professional community. Chapter 2 goes on to discuss why research into the experience of diagnosis is important, and Chapter 3 describes the specific methodology chosen to carry out this exploration. The specific aims and hypotheses of the study are set out in Chapter 4.

CHAPTER 1: Introducing Asperger's Syndrome and High Functioning Autism.

To begin to explore the experience of receiving a diagnosis of Asperger's Syndrome or High Functioning Autism in adulthood, it is important to consider the current understanding that surrounds these relatively recent diagnostic categories. Doing this allows an appreciation of the information that those who have been diagnosed must begin to decipher. All the discussions outlined below are currently present within the public domain and are readily available to those diagnosed.

1.1 What are Asperger's Syndrome and High Functioning Autism?

Asperger's Syndrome and High Functioning Autism, along with Autism, form a group of neurodevelopmental disorders called Autism Spectrum Disorders. All individuals with an Autism Spectrum Disorder are thought to share similar, albeit heterogeneously expressed characteristics. The core characteristics are commonly referred to as the 'Triad of Impairments' and include difficulties with social interaction, social communication and flexibility of thought, and the presence of strongly held restricted interests and repetitive behaviour (Wing, 1981; Wing & Gould, 1979). Individuals with Asperger's Syndrome or High Functioning Autism are differentiated from those with Autism primarily as they are of average or above average intelligence (American Psychiatric Association, 1994).

Over the last twenty years the most common conceptualisation of these disorders is that they form a continuum or spectrum, incorporating a range of abilities and expressions of the core characteristics (Wing, 1996). It is

commonly understood that at one end of the spectrum are those individuals with 'classical autism' and additional learning needs, ranging up to the other end of the spectrum with individuals with High Functioning Autism and Asperger's Syndrome (see Figure 1.1). This has led to the suggestion that Asperger's Syndrome is a 'milder' form of Autism rather than a distinct condition (Ritvo *et al.*, 2008). Asperger's Syndrome and High Functioning Autism are therefore viewed as sub-categories on the autistic spectrum (Attwood, 1998).

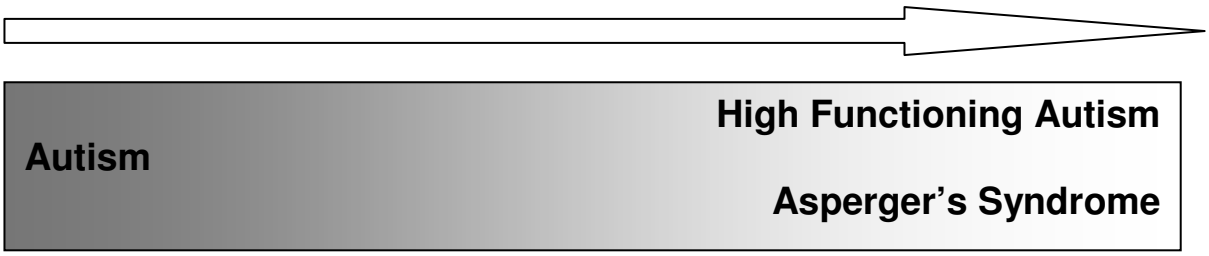

Figure 1.1: The autistic spectrum

The proponents of this understanding are calling for diagnostic categories to be reviewed and a broader category of Autism Spectrum Disorder be applied with specification of the sub-type e.g. severe, moderate, mild, Asperger's and atypical (Mcintosh & Dissanayake, 2004; Ritvo *et al.*, 2008).

1.2 What are the origins of Asperger's Syndrome and High Functioning Autism?

Asperger's Syndrome and High Functioning Autism are not modern phenomena (Frith, 1989). Frith (1989) revisits a number of famous case studies from history, including the wild boy of Aveyron, within the framework of Autism. Additionally, there have been speculations that a number of famous historical figures had an Autism Spectrum Disorder, including Albert Einstein and Alan Turing (James, 2006), and Arthur Conan

Doyle (Fitzgerald, 2005) and his creation Sherlock Holmes (Frith, 1989). However, neither Autism nor Asperger's Syndrome were described until the middle of the last century.

Leo Kanner, a psychiatrist in the United States, first described Autism in 1943 calling it 'early infantile autism' (Attwood, 2007; Gillberg, 2002). Kanner's descriptions were based on individuals with low cognitive abilities, who experienced difficulties with social interaction, and a reliance on repetitive routines and sameness (Gillberg, 2002). Around the same time in Austria in 1944, Hans Asperger, a paediatrician, published an account of a condition he called 'autistic psychopathy', using case descriptions of a number of boys he had worked with since the early 1930s (Asperger, 1991; Gillberg, 2002). His sample of children had normal cognitive and language development but showed significant difficulties with social and communication abilities (Frith, 1991).

During the aftermath of World War Two Hans Asperger's account remained hidden, while Kanner's accounts went on to be widely known. As such, for the next 40 years the focus was on low-functioning individuals with autism, resulting in clinicians overlooking those individuals who exhibited characteristics of autism but who were of average or above average intelligence (Attwood, 2007). It was not until 1981 when Lorna Wing published an account of 34 individuals who she felt matched Asperger's original descriptions that the term 'Asperger's Syndrome' was first used and interest was focused on higher functioning individuals (Gillberg, 2002; Wing, 1981). The two accounts of Kanner and Asperger have many similarities and since the introduction of Asperger's description to the wider population by

Lorna Wing in 1981, the differentiation of the two conditions has caused much debate and confusion (Ritvo *et al.*, 2008).

1.2.1 How are Asperger's Syndrome and High Functioning Autism Diagnosed?

The detection of the behavioural features of Autism Spectrum Disorders is the main focus of diagnosis (Wing, 1981). However, Asperger's Syndrome is a heterogeneous disorder, each individual is unique and there is considerable variability as to how the different core features present (Gillberg, 2002) and which features are essential for diagnosis (Wing, 1981). Some individuals present in particularly subtle and uncharacteristic ways (Gillberg, 2002). Establishing diagnostic boundaries has proved to be difficult, with different names for what appear to be very similar conditions e.g. Asperger's Syndrome and High Functioning Autism (Molloy & Vasil, 2002).

Initially only Autism was included as a diagnostic category, in the Diagnostic and Statistical Manual of Mental Disorders – 3rd Edition (DSM-III, American Psychiatric Association, 1980). The first diagnostic criteria to be written for Asperger's Syndrome were by Gillberg and Gillberg (1989), subsequently reviewed by Gillberg (1991; see Appendix 1.1) and by Szatmari *et al.* (1989; see Appendix 1.2). The increased interest in Asperger's Syndrome led to the inclusion of diagnostic criteria, alongside those for Autism, in the Diagnostic and Statistical Manual of Mental Disorders – 4th Edition (DSM-IV, American Psychiatric Association, 1994; see Appendix 1.3) and International Classification of Mental and Behavioural Disorders - 10 (World Health Organisation, 1993; see Appendix 1.4). Each criterion differs slightly, with only the Gillberg (1991) criteria continuing to closely resemble Asperger's

original descriptions (Attwood, 2007; Gillberg, 2002). High Functioning Autism is not described within the diagnostic criteria.

The diagnostic systems for both Autism and Asperger's Syndrome have been criticised for a number of reasons, particularly the requirement that if the criteria for Autism are met then the diagnosis of Asperger's Syndrome must be excluded, making it virtually impossible to give the diagnosis of Asperger's Syndrome (Gillberg, 2002). Additionally the diagnostic criteria are based upon children, yet the clinical presentation is likely to change with age (Molloy & Vasil, 2002). Even between clinicians there appear to be variations in how the diagnostic features are interpreted (Molloy & Vasil, 2002).

1.3 Are Asperger's Syndrome and High Functioning Autism different conditions?

The understanding of Autism, Asperger's Syndrome and High Functioning Autism as all being part of the same group of neurodevelopmental disorders has been considered, and the confusion around the diagnostic boundaries between Autism and Asperger's Syndrome has been discussed. However, there is also ongoing debate regarding the relationship between Asperger's Syndrome and High Functioning Autism and it is important to consider this debate in more depth.

There are two understandings of the relationship between Asperger's Syndrome and Autism. Firstly, as discussed already Asperger's Syndrome and High Functioning Autism may be conditions on the less impaired end of a continuum with Autism (Attwood, 2007). Secondly, Asperger's Syndrome

and Autism may be two separate and distinct disorders with separate underlying aetiology and developmental pathways (Rinehart *et al.*, 2002; Skuse, 2007).

To date, the question of the relationship between the two conditions remains unanswered and there continues to be a lack of clarity within the research evidence (Macintosh & Dissanayake, 2004; Ritvo *et al.*, 2008). Differences in the presentation of the features of Asperger's Syndrome and High Functioning Autism have not been consistently observed, and when adults diagnosed with both conditions are compared there appears to be a significant symptom overlap, both in type and duration (Mcintosh & Dissanayake, 2004; Ritvo *et al.*, 2008); and no consistent cognitive profile has been established for either condition (Mcintosh & Dissanayake, 2004). Anecdotally if an individual is of average or above average intelligence the diagnostic distinction between Asperger's Syndrome and High Functioning Autism tends to be made on the basis of the presence or absence of a language delay (Attwood, 2007). In diagnosis in adulthood this must be established retrospectively which poses problems for reliability, as the extent to which communication and language difficulties differentiate the two groups varies with age, with differences diminishing over time (Attwood, 2007; Eisenmajer *et al.*, 1996; Ozonoff *et al.*, 2000).

The lack of clarity around the relationship between the two conditions has led to confusion for those diagnosed, their families and for clinicians (Ritvo *et al.*, 2008). Clinicians have begun to use the diagnostic terms interchangeably (Attwood, 2007; Gillberg, 2002; Rinehart *et al.*, 2002), often based on the preferences of the individuals being diagnosed (Attwood, 2007; Gillberg,

2002). The diagnosis of Autism for some appears to hold negative connotations while Asperger's Syndrome provides more hope (Gillberg, 2002) and is thought to be helpful in explaining the difficulties of individuals who have few language problems and are not 'socially aloof' (Wing, 1981). Additionally, in some areas the diagnosis of Asperger's Syndrome does not give access to statutory supports which can lead to significant implications for the individual (Attwood, 2007; Gillberg, 2002).

Clinicians have criticised academics for trying to force a distinction between the two conditions when there seems to be considerable overlap between presentation and treatment (Attwood, 2007). Consequently, individuals of average or above average cognitive functioning who meet the diagnostic criteria for an Autism Spectrum Disorder may receive either a diagnosis of Asperger's Syndrome or High Functioning Autism, and therefore it appears appropriate to consider the experience of diagnosis in adults who receive either diagnosis.

1.4 How common are Asperger's Syndrome and High Functioning Autism?

Most epidemiological surveys of Autism Spectrum Disorders are based on the diagnostic criteria, only looking at Autism and Asperger's Syndrome (Fombonne, 2005a). However, due to shifting diagnostic definitions little is known about the actual epidemiology of Asperger's Syndrome in the wider population (Fombonne, 2005a; Ghaziuddin, 2005). There are no data pertaining to the epidemiology of High Functioning Autism as this has never been identified as a separate diagnostic category, consequently only the data available for Autism and Asperger's Syndrome are presented here.

In a recent review of epidemiological surveys of Autism Spectrum Disorders the overall prevalence of Autism Spectrum Disorders was estimated at 0.6 percent (Fombonne, 2005b). The prevalence rates of Asperger's Syndrome have been described as being lower than for Autism, although few surveys have specifically compared the prevalence rates of the two disorders, making it difficult to establish how much lower (Fombonne, 2005a). The prevalence of Asperger's Syndrome was estimated at 2.6 per 10,000 (Fombonne, 2005a), while others have suggested higher estimates of 3-4 in every 1000 children (or 30 to 40 per 10, 000; Gillberg, 2002). In Scotland around 1 in 7 of the individuals identified as having an Autism Spectrum Disorder were diagnosed as having Asperger's Syndrome (Scottish Executive, 2004). There are no separate estimates of prevalence for High Functioning Autism.

Autism Spectrum Disorders appear to be more common in boys than girls, with a male/female ratio of 4.3:1 (Fombonne, 2005b). The male to female ratio in Asperger's Syndrome is similarly skewed toward males (Gillberg, 2002). Again there are no separate data for High Functioning Autism. The estimates of the prevalence of females with Asperger's Syndrome may be too low (Ghaziuddin, 2005), possibly as a result of the more subtle presentation of the symptoms of Asperger's Syndrome in females (Attwood, 2006). There appears to be no impact of social class, race or ethnicity on the incidence of Autism Spectrum Disorders (Fombonne, 2005b).

It has been suggested that Autism Spectrum Disorders are more prevalent than previously thought (Baird *et al.*, 2006). However, the increase in prevalence has not been proven to result from an increase in incidence, but is

likely to be as a consequence of changes in the understanding and definition of the diagnosis, better identification techniques, increased service availability, and increased knowledge about Autism Spectrum Disorders in professional and lay populations (Baird *et al.*, 2006; Fombonne, 2005a; 2005b). As such there are likely to be a number of adults with an Autism Spectrum Disorder who have not been identified in childhood, but who may receive a diagnosis later in life (Royal College of Psychiatrists, 2006).

1.5 What causes Asperger's Syndrome and High Functioning Autism?

A number of explanations for Autism Spectrum Disorders have been proposed in the past. These include the 'refrigerator parenting' hypothesis where autism was considered a response to a threatening environment (Bettelheim, 1956; 1967), and the hypothesis suggesting the cause may be the measles-mumps-rubella (MMR) vaccine (Wakefield *et al.*, 1998). The current understanding of the underlying cause of Autism Spectrum Disorders is believed to be a genetic susceptibility (Gillberg, 2002; Skuse, 2007). This is consistent with Asperger's original assertion that autism was genetically transmitted, he clarified this by describing characteristics within the wider families of the diagnosed individuals, in particular in the fathers (as cited in Wing, 1981). However, genetic research to date has been unable to identify the exact genetic components (Skuse, 2007), although preliminary candidate genes have recently been identified that may underlie both Autism and Asperger's syndrome (Szatmari, 2007). The genetic susceptibility is thought to lead to changes in the early brain development of individuals with Autism Spectrum Disorders (Gillberg, 2002; Ritvo *et al.*, 2008).

As yet no clear and consistent neurological pathology has been identified for Autism Spectrum Disorders (Amarel *et al.*, 2008). Different hypotheses include the possibility that there is abnormal brain development or that there is an increase in the rate of early brain development (Amarel *et al.*, 2008). There is support for the theory that there is a difference in the way that the brain develops rather than a deficit or abnormality in Asperger's Syndrome and High Functioning Autism (Baron-Cohen, 2002). This is reflected in the developing movement emphasising respect of 'neurodiversity' and the autistic mind (Blume, 1998), driven predominantly by individuals with an Autism Spectrum Disorder (Gernsbacher, 2004; Harmon, 2004).

1.6 How are Asperger's Syndrome and High Functioning Autism understood in relation to the typically developing population?

The discussion of the causes of Asperger's Syndrome and High Functioning Autism raises the question of how the conditions are understood in relation to the typically developing population. There appear to be three main conceptualisations**:** Asperger's Syndrome and High Functioning Autism as an impairment or disability, as a difference, or as an advantage. It is likely that which conceptualisation an individual relates to will have implications for how they think about their diagnosis.

1.6.1 Asperger's Syndrome and High Functioning Autism as an impairment or disability.

During recent history the conceptualisation of Autism Spectrum Disorders as a deficit or impairment has been the dominant viewpoint (Molloy & Vasil, 2002). The impairment model is consistent with the medical understanding of Asperger's Syndrome and High Functioning Autism, and has at its centre

the understanding that both conditions are disabilities (Baron-Cohen, 2002). The medical viewpoint is based upon an illness model, whereby causation in Asperger's Syndrome and High Functioning Autism is linked to a neurologically based impairment or abnormality, which is located within the individual (Molloy & Vasil, 2002).

The description of the core characteristics of Autism Spectrum Disorders as being a 'Triad of Impairments' (Wing, 1981; Wing & Gould, 1979) is consistent with the medical understanding of the condition. The 'Triad of Impairments' has had a significant influence on the development of the diagnostic criteria for both Autism and Asperger's Syndrome (Aylott, 2000). It is also apparent in some of the cognitive theories that have developed to explain the difficulties associated with Autism Spectrum Disorders, two influential cognitive theories which provide explanations in terms of impairments in specific cognitive functions are described below.

The first of these, the 'theory of mind' hypothesis, is the most widely known and focuses on a specific cognitive impairment. It is based on the understanding that the ability to 'mind-read' or represent mental states is delayed in individuals with Autism Spectrum Disorders (Baron-Cohen *et al*., 1985; Leslie, 1995). Children typically develop this ability around the age of four, when a child begins to understand that other people have beliefs and desires and that it is these mental states which determine behaviour and not the physical state of the world (Baron-Cohen *et al*., 1985; Leslie, 1995). The 'theory of mind' explanation can explain the social and communication difficulties apparent in Autism Spectrum Disorders, particularly highlighting why individuals may be confused or frightened in social situations, however,

it does not provide explanation for the non-social aspects of Autism Spectrum Disorders (Baron-Cohen, 2008).

The other theory postulated to explain the mechanism of Autism Spectrum Disorders in terms of underlying cognitive impairment is the 'executive dysfunction' theory (Ozonoff *et al*., 1991). The theory assumes that some characteristics of Autism Spectrum Disorders such as 'repetitive behaviour' and desire 'for sameness' are as a result of impairments within the frontal lobes, leading to an inability to shift attention. It has been suggested that the 'executive dysfunction' theory presents a negative view of Autism Spectrum Disorders (Baron-Cohen *et al*., 2002).

There are advantages and disadvantages associated with the understanding of Asperger's Syndrome and High Functioning Autism as a deficit or impairment. Importantly, there is the possibility that this understanding may lead to a view of Asperger's Syndrome and High Functioning Autism which is largely negative and this could lead to more negative experiences (Aylott, 2000). However, this understanding has been valuable in ensuring that individuals with the diagnosis are provided with access to appropriate support (Baron-Cohen, 2002; Molloy & Vasil, 2002), and for providing a structure to essential research into Autism Spectrum Disorders (Molloy & Vasil, 2002).

1.6.2 Asperger's Syndrome and High Functioning Autism as a difference.

The conceptualisation of Asperger's Syndrome and High Functioning Autism as a difference is built upon the Autism Spectrum understanding described earlier (Wing, 1996). It has been suggested that the spectrum

continues into the typically developing population, where characteristics associated with Autism Spectrum Disorders can be seen in varying degrees. This theory proposes that the symptoms of Autism and Asperger's Syndrome are not as a result of pathological development but are normal traits which have become expressed to an extreme degree in certain individuals, suggesting that there is a 'broader autistic phenotype' (Baron-Cohen, 2002; see Figure 1.2).

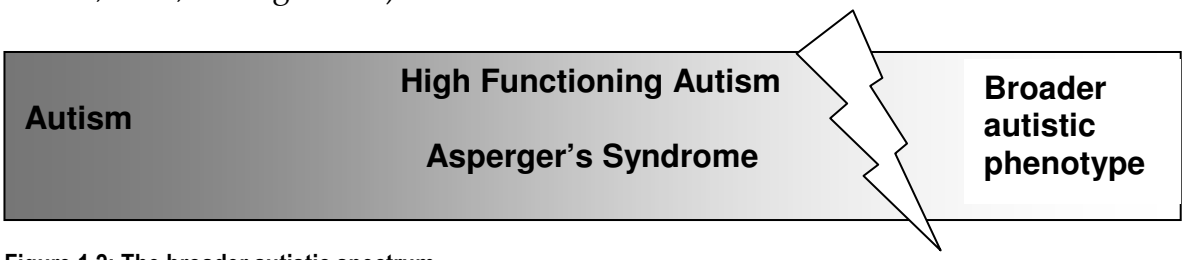

Figure 1.2: The broader autistic spectrum

It has been questioned as to whether Asperger's Syndrome and High Functioning Autism are necessarily disabilities (as the medical model suggests) but are *differences* in cognitive style, with individuals with the diagnosis being more focused toward 'things' rather than 'people' (Baron-Cohen, 2002). Baron-Cohen (2002) questions whether being focused on 'things' is only disabling in a world where we are expected to be person focused, in other environments a cognitive style focused on 'things' has enormous practical value as evident in mathematical developments. This understanding has led to the consideration of the role of society in creating the understanding that Asperger's Syndrome and High Functioning Autism are disabling (Aylott, 2000; Baron-Cohen, 2002; Molloy & Vasil, 2002).

Happe (1994; 1999) and Baron-Cohen (2002) have championed the understanding that Asperger's Syndrome in particular may be viewed as a different cognitive style. The two cognitive theories they have developed relate the characteristics of Autism Spectrum Disorders to individual

differences seen within the entire population rather than to qualitatively and categorically distinct changes (Baron-Cohen, 2008). Both theories are discussed below.

The 'central coherence' theory differs from the above theories as it does not offer an explanation in terms of cognitive impairments, but in terms of a variation in a cognitive style present in the entire population (Happe, 1994). It is suggested that individuals with Autism Spectrum Disorders have weak central coherence, which means they have difficulty in seeing the overall context of a picture and tend to focus on the details as they may be processing information at a local rather than a global level (Happe, 1994). This theory explains the socialisation and communication difficulties associated with Autism Spectrum Disorders in terms of an individuals' difficulty with grasping the context and therefore extracting the overall meaning from a social situation (Happe, 1994). It also explains relative strengths in those tasks which require attention to detail (Happe, 1994).

The 'empathising-systemising theory' is the second theory to suggest an explanation in terms of a difference in cognitive style. It suggests there are two underlying psychological dimensions on which we all vary (Baron-Cohen, 2002). Empathising involves two processes, firstly identifying emotions and thoughts in others, and then responding to these appropriately (Baron-Cohen, 2002). Systemising is the drive to analyse and build systems, for instance technical, abstract, or natural systems (Baron-Cohen, 2002). A deficit in empathising has been suggested to explain the social and communication difficulties with autism. However, systemising has been found to be intact or even superior in individuals with Autism Spectrum

Disorders relative to typically developing age-matched peers (Baron-Cohen *et al*., 2003).

Similar to the deficit and impairment understanding of Asperger's Syndrome and High Functioning Autism**,** advantages and disadvantages of the difference conceptualization have been raised. It has been suggested that the understanding of Asperger's Syndrome and High Functioning Autism as a cognitive difference should be encouraged as it is value-free and destigmatises Autism Spectrum Disorders (Baron-Cohen, 2002; 2008), and may be useful for explaining the diagnosis to individuals and supporting them through the adjustment process (Attwood, 2007). However, implicit to this understanding is that Asperger's Syndrome is less severe than Autism or High Functioning Autism (Gillberg, 2002). This understanding has raised concerns with some clinicians, as outcome can be highly variable even for high functioning individuals (Howlin, 2000) and many individuals continue to require high levels of support to cope with everyday life (Gillberg, 2002).

1.6.3 Asperger's Syndrome and High Functioning Autism as an advantage.

The understanding of Asperger's Syndrome and High Functioning Autism as an advantage builds upon the difference conceptualisation. It acknowledges the many strengths associated with having Asperger's Syndrome and High Functioning Autism (Molloy & Vasil, 2002; Attwood, 2007). It is a relatively recent conceptualisation and one driven by those individuals with Asperger's Syndrome and High Functioning Autism, and is not inconsistent with the 'empathising-systemising' theory where strengths in systemising are emphasised (Baron-Cohen, 2002).

Online communities have been an immensely valuable resource for individuals with Asperger's Syndrome and High Functioning Autism. Many websites and forums have been created which provide opportunities for sharing ideas and understanding about Asperger's Syndrome and High Functioning Autism. Some of the discussions on these websites have focused on Asperger's Syndrome as an advantage or superior level of cognitive development, particularly in respect of special abilities for original thought. Suggestions have even been made that as a result of the opportunity for original thought shown by individuals with Asperger's Syndrome, that it could be the next evolutionary stage (Attwood, 2006).

1.7 Summary

Current understanding of Asperger's Syndrome and High Functioning Autism available within the public domain has been considered in this chapter, including discussing the origins, diagnostic boundaries, epidemiology, causes, and theoretical conceptualisations of Asperger's Syndrome and High Functioning Autism. Inherent in these discussions has been the confusion and lack of clarity surrounding the conditions. Much of what has been discussed above is available in 'self-help' type books relating to Asperger's Syndrome and High Functioning Autism (e.g. Attwood, 2007; Frith, 1991; Holliday Willey, 1999). Therefore, there is the potential for considerable variance in how Asperger's Syndrome and High Functioning Autism are understood by those receiving a diagnosis.

The following chapter will focus specifically on diagnosis in adulthood and explain why it is an important area for investigation. The literature surrounding the experience of diagnosis in this population will be explored

along with discussion of potential variation in an individual's experience based upon how they conceptualise the diagnosis.

CHAPTER 2: Why are we interested in the experience of diagnosis in adulthood?

There has been little research conducted on the experience of receiving a diagnosis of Asperger's Syndrome or High Functioning Autism in adulthood, or on how the diagnosis is understood by those that receive it. Before describing this research there will be a discussion of the motivations for diagnosis in adulthood and why it might not occur until this stage in life.

2.1 Diagnosis in adulthood

It is important to understand why a diagnosis of Asperger's Syndrome or High Functioning Autism may not be received until adulthood, and also to consider the possible consequences of late diagnosis. This allows an appreciation of the experiences of adults receiving a diagnosis of Asperger's Syndrome and High Functioning Autism.

2.1.1 Why may diagnosis not occur until adulthood?

The features of Asperger's Syndrome and High Functioning Autism are present from early childhood, but may not be detected at this point as they can be subtle and uncharacteristic (Gillberg, 2002). There are many possible explanations for why an individual may then receive a diagnosis of Asperger's Syndrome or High Functioning Autism in adulthood, three possible pathways to diagnosis have been outlined below as illustration.

Hans Asperger outlined that some individuals may find that their special interests bring meaningful employment or help them to sustain intimate relationships (as cited in Wing, 1981). Such individuals may have passed

through life, feeling different and misunderstood, but managing to work and have relationships. It may have been that a chance introduction to Asperger's Syndrome or High Functioning Autism (e.g. reading, Television, internet), drove them to seek out a diagnostic assessment (e.g. Holliday Wiley, 1999; 2006).

Other individuals similarly may not have experienced particular difficulties until there were points of transition or increased stress (e.g. divorce, loss of job, moving out of home, attending university) in their life (e.g. Mitchell, 2005). At this point well established routines or supports may break down and an individual may find they struggle with everyday living and experience mental health difficulties (Attwood, 2007). This may lead to them seeking help from health services who may recommend a referral to a diagnostic service.

It is also possible that an individual has struggled throughout their life with relationships and communication, and never achieved their full potential. They may have experienced significant mental health difficulties, including depression and anxiety, leading to them accessing mental health services where they were deemed difficult to categorise (Gillberg, 2002). Or they may have been misdiagnosed with psychiatric conditions such as schizophrenia, or with another pervasive developmental disorder, e.g. Attention Deficit Hyperactivity Disorder (Attwood, 2007). In a recent study up to 18 percent of individuals in three psychiatric hospitals were identified as having socialisation and communication difficulties to an extent that they would meet the criteria for an Autism Spectrum Disorder (Hare *et al*., 2000). Another study found a percentage of psychiatric outpatients diagnosed with

psychosis, obsessive-compulsive disorder and personality disorder to have a diagnosis of Asperger's Syndrome or Autism Spectrum Disorder (Nylander & Gillberg, 2001). The relatively recent discovery of Hans Asperger's work (Wing, 1981) which highlighted that autism spectrum disorders could be associated with individuals of average or above average intelligence, may have contributed to these missed diagnoses.

2.1.2 What are the potential positive consequences of diagnosis in adulthood?

The main motivation for diagnosing Asperger's Syndrome and High Functioning Autism, at any age, appears to be the positive implications it may have primarily for the individual, but also for their family and friends or colleagues.

The diagnosis, and the process of learning about Asperger's Syndrome and High Functioning Autism, may lead to better self-understanding and an appreciation of ways in which they think differently from other people (Attwood, 2006). The framework that the diagnosis of Asperger's Syndrome and High Functioning Autism provides, can give an alternative explanation for past difficulties, so rather than believing that they are 'bad' or 'mad' they can reflect on the diagnosis of Asperger's Syndrome or High Functioning Autism (Attwood, 2006; Aylott, 2000; Holliday Willey, 1999). Additionally, future difficulties can also be interpreted in the light of this framework. A number of clinicians advocate an approach to explain the diagnosis that focuses on both the qualities and talents an individual has, before discussing the associated difficulties (Attwood, 2006; Gray, 1996; Vermeulen, 2001).

For some people, receiving a diagnosis of Asperger's Syndrome or High Functioning Autism may have practical consequences, opening up avenues for accessing appropriate support in education and employment (Attwood, 2006). The diagnosis can help to inform better decision making within relationships and careers (Attwood, 2006). The diagnosis may provide opportunity for accessing support groups, where advice can be sought from other individuals with Asperger's Syndrome and High Functioning Autism, and potentially can encourage a sense of belonging or 'fitting in' to a distinct and valued culture (Attwood, 2007; Punshon, 2006).

2.1.3 What are the potential negative consequences of diagnosis in adulthood?

The author was unable to identify any studies which compared the outcome of individuals who received a diagnosis of Asperger's Syndrome or High Functioning Autism in childhood with those who received the outcome in adulthood. However, it has been suggested that the earlier an individual receives the diagnosis and is provided with information that helps them understand the condition the more positive the outcome (Aylott, 2000; Portway & Johnson, 2005). Late diagnosis and limited intervention has been associated with under-achievement, high dependency on parents, low self-esteem, rejection, high anxiety, depression and suicidal tendencies (Howlin, 2000; Portway & Johnson, 2005).

In general, individuals with Autism Spectrum Disorders have increased vulnerability to mental health difficulties, particularly regarding anxiety and depression (Berney, 2005). Depression is the most common mental health difficulty that occurs across the lifespan of someone on the autistic spectrum,

and appears to affect higher-functioning individuals more significantly (Ghaziuddin, 2005). It has been suggested that the high occurrence may be related to delays in diagnosis and the accumulation of negative experiences (Barnard *et al*., 2001; Punshon, 2006); limited social protective factors (Royal College of Psychiatrists, 2006); difficulty in recognising and acknowledging their own disabilities (Gillberg, 2002); and feelings of inadequacy and stigma (Berney, 2005).

It is possible that the outcome may be more negative for those diagnosed in adulthood, if throughout development an individual has struggled with difficulties for which they have no explanation or support, leaving them confused with a subjective sense of 'not fitting in' or 'being different' (Molloy & Vasil, 2004; Punshon, 2006). This may lead to them forming detrimental conclusions about themselves such as the belief that they are different because they are 'mad, bad or stupid' (Aylott, 2000). It has been suggested that receiving a diagnosis may be a damaging blow to an individual who may already have a fragile self-esteem, and this may trigger depression (Whitaker, 2006). Additionally, how the diagnosis is understood by others is very important. Misunderstandings of the characteristics of Asperger's Syndrome and High Functioning Autism may lead to others ridiculing or limiting their expectations of the individual (Attwood, 2006).

A recent qualitative study by Portway and Johnson (2005) has explored the risks associated with having Asperger's Syndrome. The researchers interviewed 25 young adults and their parents and identified the key theme of 'not quite fitting in'. They found that all their participants were to some degree unhappy, anxious or depressed. The researchers describe a complex

interplay between feelings about oneself and the perceptions of others, leading to risks associated with having Asperger's Syndrome. Everyday risks appeared to be characterised by misunderstanding and being misunderstood, isolation, loneliness, and perception of 'difference'. Longer term risks were explained as resulting from a combination of the accumulation of adverse experiences and the underlying core disability of Asperger's Syndrome, and included underachievement, prolonged dependency on parents, and mental health difficulties including depression, anxiety, obsessions and suicidal ideation (Portway & Johnson, 2005). It could be hypothesised that the beliefs an individual holds about their diagnosis may impact upon their adjustment and on their mental health.

2.2 How is diagnosis of Asperger's Syndrome and High Functioning Autism in adulthood experienced?

A number of reasons why an individual may receive a diagnosis in adulthood have been considered, and important positive and negative consequences of this late diagnosis discussed. The clinical research into the experiences of adults who have received a diagnosis of Asperger's Syndrome or High Functioning Autism will now be outlined. Due to the paucity of research into this area autobiographical accounts by individuals who have received the diagnosis in adulthood will also be considered.

2.2.1 Clinical research into the experience of diagnosis in adulthood

Research into the experience of diagnosis in adults is sparse, with only a handful of qualitative studies (Cousins, 2001; Molloy & Vasil, 2004; Punshon, 2006) involving small numbers of participants in exploratory investigation.

To date no further research has built upon these qualitative studies in more systematic investigation.

Cousins (2001, unpublished doctoral thesis as cited in Punshon, 2006) completed a qualitative study investigating the experiences of adults who had been diagnosed with either Asperger's Syndrome or High Functioning Autism. Eight participants were recruited through an internet support group for adults reporting to be diagnosed with an 'Autism Spectrum Condition'. The interviews were conducted online in secure 'chat rooms'. Analysis led to the extraction of seven main themes. The themes were 'Being an outsider', 'In search of an explanation', 'Revelation', 'A search for meaning, 'Support', Building a framework', and 'Identity' (Cousins, 2001 as cited in Punshon, 2006).

Of the seven themes the first, 'Being an outsider', related to the beliefs individuals held about themselves prior to the diagnosis. For instance an individual's subjective feeling of difference from other people and the blaming of self and others for their difficulties. The next two themes described the beliefs an individual begins to develop about themselves in relation to Asperger's Syndrome and High Functioning Autism. The theme 'A search for meaning' related to adults gathering information about Asperger's Syndrome and High Functioning Autism, enabling them to make sense of current and past difficulties. The 'Building a framework' theme related to participants discussions about the differences and similarities they share with typically developing individuals. The 'Revelation' described the immediate feeling of relief that the adults felt on receipt of the diagnosis (Cousins, 2001 as cited in Punshon, 2006).

The final theme of 'Identity' incorporated the sense of belonging and acceptance that the individuals felt as a result of receiving the diagnosis, including the subjective feeling of 'fitting in', the provision of an explanation of their behaviours for both themselves and others in respect of the diagnosis, and the expression of beliefs about what Asperger's Syndrome and High Functioning Autism are, for instance a difference rather than a deficit (Cousins, 2001 as cited in Punshon, 2006). A major limitation of the study was the researcher's inability to confirm the diagnoses, and the study may have also been limited by the reliance on only one recruitment channel.

Molloy and Vasil (2004) carried out a qualitative study using a narrative approach to investigate the life stories of six adolescents[1] who had received a diagnosis of Asperger's Syndrome. The motivation for using a narrative approach was to 'give a voice' to those living and experiencing Asperger's Syndrome. The adolescents ranged in age from 12 to 18, and the age at which they received a diagnosis varied from 4 to 14. The six main emerging themes were 'Diagnosis as a sense-making narrative', 'Labelling and identity', 'Socialising and making friends', 'The dilemma of schooling', 'Family life', and 'Rages and blues'.

The theme of 'Diagnosis as a sense-making narrative' related to how the diagnosis led to greater understanding by the families of the adolescents. It incorporated a process of learning about Asperger's Syndrome and re-evaluating previous experiences, allowing for an alternative and more positive self-image to be developed. This may be similar to Cousins (2001) 'A

[1] Although this study described the experiences of adolescents and not adults, the findings were deemed of interest and comparable with those of the other studies, it was therefore included for discussion.

search for meaning' and 'Building a framework themes'. Associated with this theme were the feelings individuals experienced when they received the diagnosis, including relief, shock, disbelief and mixed feelings.

The theme of 'Labelling and Identity' related to how and to what extent the adolescent identified with their diagnosis and defined themselves by the label. It appeared to build upon the sense-making theme, as individuals identified with different traits and aspects of Asperger's Syndrome. Important questions that the authors felt the adolescents were addressing included whether they accepted the diagnosis and whether they considered Asperger's Syndrome a disability. The majority of the adolescents saw themselves as being different rather than having a disability, and most identified with associated strengths and benefits including access to services and not just the potential difficulties. This theme shows particular similarities with the 'Identity' theme (Cousins, 2001) previously discussed.

Limitations of this study included the wide range of nationalities with three individuals being from the United Kingdom and six from Singapore, which may have had unique implications for how individuals experience their diagnosis. Additionally, there was no formal analysis of the data.

Punshon (2006) conducted a qualitative study using a phenomenological approach to explore the experiences of ten adults who had received a diagnosis of Asperger's Syndrome in adulthood. The participants were recruited from a local service for adults with Asperger's Syndrome, all individuals had been diagnosed by the service and were continuing to access support. The six major themes extracted were 'Negative life experiences',

'Experience of services (pre-diagnosis)', 'Beliefs about the symptoms of Asperger's Syndrome', 'Identity formation', 'Effects of diagnosis on beliefs', and 'Effect of societal views of Asperger's Syndrome'.

The first theme, 'Negative life experiences' was drawn from individuals' frequent experience of negative life events and mental health difficulties prior to receiving the diagnosis. Importantly in the 'Experiences of services (pre-diagnosis)' theme adults reported feeling blamed and misunderstood for their difficulties. Both of these themes appear to link with the 'Beliefs held about the symptoms of Asperger's Syndrome'. This theme relates to beliefs about the symptoms prior to the diagnosis of Asperger's Syndrome being considered as an explanation. They revolved around feelings of 'difference' and 'not fitting in', and led to them feeling there was 'something wrong' with them which they must try to cover up. The theme of 'Identity formation' indicated how prior to diagnosis without a framework to understand their difficulties they internalised the negative statements made by others and their feelings of 'difference'.

The theme of 'Effect of diagnosis on beliefs' described a mixture of positive and negative changes. Importantly the diagnosis was seen to provide a framework from which individuals could understand their past and present difficulties. It also allowed for positive aspects of the condition to be acknowledged. In this theme the researcher highlights the differing viewpoints of the participants, which included seeing Asperger's Syndrome as a disability, a difference, and a advantage. The reference to these different viewpoints is similar to that discussed previously in themes relating to identity (Cousins, 2001; Molloy & Vasil, 2004). The researcher concluded that

the emotional reactions to the diagnosis, including elation, relief, loss and anger, appeared to be determined by the participant's previous negative experiences and their viewpoint. The importance of societal views was highlighted in the 'Effect of societal views of Asperger's Syndrome' theme, particularly with reference to stereotypical representations and the misunderstanding of the condition within the wider population.

Punshon (2006) drew the conclusion from the study that the beliefs an individual held about the symptoms of Asperger's Syndrome were influenced by pre-diagnostic life experiences, previous experience of services, and their feelings when they received the diagnosis. In turn it was suggested the beliefs held about Asperger's Syndrome influenced the formation of an individuals' identity. The study was limited by the reliance on only one channel for recruitment. It is possible that the sample was biased toward individuals who required considerable support to adjust to a diagnosis and who had opportunities to discuss what having Asperger's Syndrome means. The experiences of adults who have not accessed services may be different.

All three studies show similarities in the identified themes. Both Cousins (2001) and Punshon (2006) highlighted the importance of an individual's experiences prior to receiving the diagnosis. All the studies (Cousins, 2001; Molloy & Vasil, 2004; Punshon, 2006) identified a process of 'sense-making' and of gathering information about Asperger's Syndrome, which allowed the re-interpretation of previous and current experiences. Each study then identified a process involving the re-evaluation of ones identity through the acceptance of the diagnosis and the identification with certain traits

associated with Asperger's Syndrome (Cousins, 2001; Molloy & Vasil, 2004; Punshon, 2006). All studies referred to different conceptualisations of Asperger's Syndrome and High Functioning Autism, e.g. disability, difference, advantage, and these beliefs were linked to a post-diagnostic identity development.

2.2.2 Autobiographical accounts of the experience of diagnosis in adulthood

There are increasing numbers of adult accounts of diagnosis of Asperger's Syndrome and High Functioning Autism in the public domain (Birch, 2003; Holliday Willey, 1999; Mitchell, 2005; Purkis, 2006). A number of these accounts have been considered and attempts have been made to draw links with the clinical research described above.

Three autobiographical accounts (Birch, 2003; Holliday Willey, 1999; Mitchell, 2005) by adults who had 'discovered' Asperger's Syndrome themselves and then sought out a formal diagnosis to get official clarification, highlight the themes of information gathering, and 'sense making' described in the clinical research (Cousins, 2001; Molloy & Vasil, 2004; Punshon, 2006). Finding out about Asperger's Syndrome had led to them seeking out information about the condition. This information allowed them to re-interpret their lives and experiences in positive, new, understandable and logical ways. They described feelings of difference and 'not fitting in' while growing up. The diagnosis helped them to understand why they had felt different, and allowed them to dismiss their more negative, pre-diagnostic understandings of themselves as chronic failures (Mitchell, 2005), or as crazy or stupid (Birch, 2003).

Consistent with the clinical research that recognises identity formation as an important theme (Cousins, 2001; Molloy & Vasil, 2004; Punshon, 2006), they had all explored the strengths and difficulties associated with Asperger's Syndrome and related them to different aspects of their identity (Birch, 2003; Holliday Willey, 1999; Mitchell, 2005). The overall feeling toward the diagnosis was positive and they all discussed having positive reactions to their diagnosis, including feeling that it was the most defining moment in life (Mitchell, 2005) and that it was a 'revelation' (Birch, 2003). Liane Holliday Willey (1999) in particular conceptualises Asperger's Syndrome positively, fully appreciating the associated advantages and strengths, and focussing on a framework of difference.

The autobiographical accounts described above are overwhelmingly. There are limited autobiographies which discuss less positive outcomes. One autobiographical account (Purkis, 2006), by a young woman diagnosed in her twenties, described how she initially refused to accept her diagnosis. Importantly, she had not discovered Asperger's Syndrome herself but had received the diagnosis following repeated referrals to mental health services. Her denial appears to have been driven by a desire to be the same as others. Although she described relief and felt the diagnosis explained the difficulties in her life, she said that the knowledge that she was fundamentally different from others and that this was life-long and she could never change was overwhelming (Purkis, 2006). Negative beliefs about the life-long nature of Asperger's Syndrome and High Functioning Autism have been highlighted as important to post-diagnostic reactions (Georgiou, 2006).

It is possible that at the time for this young woman, the negative beliefs she held about Asperger's Syndrome meant that the sense making process and subsequent identity formation (Cousins, 2001; Molloy & Vasil, 2004; Punshon, 2006;) were more problematic. Later in her account she described that as she met more people with Asperger's Syndrome and learnt more about it she moved from being ashamed and feeling it was a dirty secret toward accepting it was part of her and had influenced many positive aspects of her personality. This account illustrates the process of 'sense making', gathering of information and 'identity formation' (Punshon, 2006; Cousins, 2001; Molloy & Vasil, 2004) as a long-term process with different conclusions drawn at different times.

For children and young people receiving the diagnosis a considerable amount of time in their early years may be spent learning that they have the diagnosis and coming to terms with the consequences of having it (Molloy & Vasil, 2002). It is likely that for adults this process will take time as well. The information gathered from the autobiographical accounts suggests that there may be differences in this process dependent on whether the diagnosis was self-motivated following the 'discovery' of Asperger's Syndrome (Birch, 2003; Mitchell, 2005), or as a result of professional intervention (Purkis, 2006).

The autobiographical accounts support in particular the themes identified by the clinical research that surround 'sense-making' and 'information gathering' (Punshon, 2006; Cousins, 2001; Molloy & Vasil, 2004). They support the link between the understanding of Asperger's Syndrome and High Functioning Autism and how it is integrated with an individuals'

identity. The importance of the beliefs an individual holds about Asperger's Syndrome and High Functioning Autism will be discussed further below.

2.3 Are the beliefs held about Asperger's Syndrome and High Functioning Autism important?

The clinical research and the autobiographical accounts all indicate a process of sense-making and information gathering that occurs following diagnosis. This process appears to determine the beliefs that are held about Asperger's Syndrome and High Functioning Autism. These beliefs are likely to influence the reaction to diagnosis (Punshon, 2006) and how the diagnosis is integrated and understood within the context of an individuals' identity (Cousins, 2001; Molloy & Vasil, 2004; Punshon, 2006). However, what these beliefs actually incorporate remains vague. Broadly they have been associated with the conceptualisations of Asperger's Syndrome and High Functioning Autism as a disability, a difference, and a advantage (Punshon, 2006). These conceptualisations have been discussed in more depth in Chapter 1.

It is likely that following diagnosis the beliefs an individual holds will have implications for how they use and adjust to this new framework. If they perceive the difference to be negative then this may pose subsequent problems for the development of a positive self-identity in the context of the diagnosis (Aylott, 2000). The clinical research indicated the importance of previous experience on developing beliefs, for example if they have previously been able to find a niche in employment then they may view having Asperger's Syndrome or High Functioning Autism in a more positive frame. Where high-functioning individuals have shown positive outcome it has been as a consequence of their special interests which have allowed them

to build social relationships (Howlin, 2000) potentially giving them a more positive view of Asperger's Syndrome and High Functioning Autism.

Additionally, clinicians supporting individuals through diagnosis emphasise the importance of this process of finding out about Asperger's Syndrome and High Functioning Autism. As described earlier many encourage a focus on the strengths and advantages, followed by discussion of the difficulties (Attwood, 2006; Gray, 1996; Vermeulen, 2001). Some clinicians have suggested that to help adults diagnosed with an Autism Spectrum Disorders develop a positive self-identity, the condition should be understood less from the perspective of an impairment or deficit model (Aylott, 2000), and the conceptualisation based on difference encouraged (Attwood, 2006; 2007). This focus by clinicians further emphasises the findings from clinical research that the beliefs an individual holds about themselves in relation to the diagnosis of Asperger's Syndrome and High Functioning Autism is important. It is likely that this is due to the influence these beliefs may have on adjustment and outcome.

2.4 Summary

This chapter has discussed why diagnosis may occur in adulthood, and the positive and negative consequences associated with diagnosis later in life. **C**urrent clinical research into the experience of diagnosis was reviewed alongside a number of recent autobiographical accounts of diagnosis in adulthood. The clinical research identified the importance of the process of 'sense-making' and 'information gathering', and the subsequent beliefs that are held about Asperger's Syndrome and High Functioning Autism, on the experience of diagnosis and subsequent identity formation. The

autobiographical accounts began to support the possibility that differences in the beliefs held may have implications for how the diagnosis is accepted and reacted to, and raised questions for the implications for longer-term outcome.

However, although the clinical research alluded to the beliefs held the explanation of the actual content of the beliefs was vague. There is acknowledgement of the broad conceptualisations of disability, difference and advantage (Cousins, 2001; Punshon, 2006) but no further specification. Chapter 1 highlighted the breadth of information there is to cover when gathering information on Asperger's Syndrome and High Functioning Autism, and identified the current confusion and lack of clarity surrounding the conditions. This emphasised the potential for considerable variance in how Asperger's Syndrome and High Functioning Autism could be understood.

It appears that there is an importance for current research to explore further the conceptualisations, beliefs, and viewpoints of those who have been diagnosed with Asperger's Syndrome and High Functioning Autism in adulthood. In Chapter 3 the methodology used to carry out this exploration will be considered.

CHAPTER 3: Introduction to Q-methodology

This study employed a Q-methodology (Stephenson, 1953) to explore the beliefs adults hold about Asperger's Syndrome or High Functioning Autism when they have received the diagnosis in adulthood. As Q-methodology is a relatively unknown methodology an initial introduction to the methodology has been described, including a summary of its background, a description of the key procedural techniques and the relevant advantages and limitations are discussed.

3.1 History of Q-methodology

Q-methodology was first outlined by William Stephenson (Stephenson, 1953), who had developed the methodology out of the work he had carried out as Charles Spearman's assistant on the development of factor analysis (Brown, 1997). He had been motivated by a general dissatisfaction with the direction of psychological research at the time, which he felt was very much focused on hypothesis testing at the expense of the understanding of subjectivity (Watts & Stenner, 2005). He believed that psychology required an 'attitude of curiosity' when searching for discoveries, as well as a focus on hypothesis testing and rigorous scientific enquiry (Stephenson, 1953). Therefore, he sought out a scientific method for systematically examining human subjectivity (McKeown & Thomas, 1988; Stephenson, 1953; Watts & Stenner, 2005).

Q-methodology, incorporates two unique techniques, the Q-sorting procedure for data collection and the Q-factor analysis procedure which conducts pattern analysis through by-person factor analysis (Watts &

Stenner, 2005). These techniques are designed to be used in conjunction with each other as a holistic methodology, not independently. However, Q-methodology has been frequently misused with the Q-sort technique being abstracted and used without an understanding of the wider methodology (McKeown & Thomas, 1988; Watts & Stenner, 2005). Unfortunately these misrepresentations of Q-methodology have often received greater publicity than the original methodology and this has led to misunderstanding within psychology and social sciences (McKeown & Thomas, 1988; Watts & Stenner, 2005).

However, in recent years Q-methodology appears to be of increasing interest as a viable methodology in psychological research, mainly as a result of the qualitative revolution within psychological research, which has allowed for the recognition of the significant commonalities of understanding the complete Q-methodology shows with modern qualitative research (Brown, 1997; Stenner & Watts, 2005). Namely this is its rejection of hypothetico-deductivism and its compatibility with a social constructivist approach (Curt, 1994; Stainton Rogers, 1991) There have been recent publications by qualitative psychologists encouraging the wider use of Q-methodology within the discipline (e.g. Shemmings, 2006; Watts & Stenner, 2005), and an increasing number of published studies within psychological research. This includes studies looking at quality of life (Stenner *et al.*, 2003); experiences of neuroleptic medication in patients with schizophrenia (Day *et al.*, 1996); engagement techniques in Clinical Psychology (Lister & Gardner, 2006); understanding of the experience of voice hearing (Jones *et al.*, 2003); understanding of Down's Syndrome (Bryant *et al.*, 2006) and Irritable Bowel

Syndrome (Stenner *et al*., 2000); and the evaluation of person-centred planning by people with an intellectual disability (Combes *et al*., 2004).

3.2 Description of Q-methodology

3.2.1 What is Q-methodology?

Q-methodology is based on an understanding that an individual's subjective point of view about a topic of interest can be communicated to others (McKeown & Thomas, 1988; Stephenson, 1953). It provides a mathematical means by which different individuals' points of view can be represented and systematically compared, to allow the identification of common-ways in which a topic of interest is understood (McKeown & Thomas, 1988). To achieve this Q-methodology combines both qualitative and quantitative techniques, and has been described as '*qualiquantalogical'* due to this unusual mixing of methods (Stenner & Stainton Rogers, 2004 cited in Watts & Stenner, 2005).

3.2.2 What are the main techniques of a Q-methodological study?

Q-methodology has two essential components (McKeown & Thomas, 1988; Stephenson, 1953). The first is the Q-sort which is the qualitative aspect of the study and the method by which an individual's point of view is captured and represented (Stephenson, 1953; Watts & Stenner, 2005). The second is the Q-factor analysis, which is the quantitative aspect of the study and the mathematical means by which the different points of view can be systematically compared (Stephenson, 1953; Watts & Stenner, 2005). Only when these two techniques are combined is Q-methodology appropriately applied (Watts & Stenner, 2005).

The Q-sort was designed as a means of capturing and representing an individual's point of view about a topic (Stephenson, 1953). To do this an individual orders (or sorts) a set of statements[2] based upon their agreement with each statement relative to all the other statements (Brown, 1997; Stephenson, 1953; Watts & Stenner, 2005). Each statement normally includes a proposition or opinion, which reflects a particular point of view about the topic of interest (McKeown & Thomas, 1988). The individual must decide how to make sense of the ambiguity, lack of clarity and themes incorporated within the set of statements (Stainton Rogers, 1991). The end result is a representation or model of the individual's point of view about the topic of interest, as captured through their sorting of the set of statements (Brown, 1997; Stephenson, 1953).

Q-factor analysis is the second main technique and the quantitative aspect of a Q-methodological study (McKeown & Thomas, 1988). It uses mathematical factor analytic techniques to compare the Q-sorts and identify common-ways in which the statements have been sorted. Q-factor analysis differs from conventional factor analysis in a fundamental way, it correlates and factor-analyses *people* and not individual items or tests (McKeown & Thomas, 1988; Stephenson, 1953). Therefore the factors extracted are in fact groupings of individuals who have made sense of the topic of interest (based on their sorting of the statements) in a similar way (McKeown & Thomas, 1988; Watts & Stenner, 2005).

3.2.3 What are the main stages of a Q-methodological study?

[2] It is most common, particularly within a qualitative and psychological context, for statements to be used as the sorting material (Watts & Stenner, 2005). However, it is possible to use pictures, photographs, single words (McKeown & Thomas, 1988). For ease of discussion statements will only be referred to throughout.

Although there are two main techniques within Q-methodology, there are a number of necessary stages within each of these techniques. Five stages can be identified: *concourse* collection; *Q-set* selection; participant selection; the *Q-sorting* procedure; and *Q-factor* analysis and factor interpretation. Each stage will be outlined below and discussed in more detail.

3.2.3.1 Concourse collection

This involves the collection of statements representing the current understandings, beliefs and opinions held about the topic of interest. This entire collection is referred to as the *concourse* and is the basis from which the statements used in the Q-sort are selected (Stephenson, 1953). The concourse should be wide and incorporate public opinion and gossip through to current debate within the scientific and medical community (Brown, 1997). A number of sources can be used, including academic literature, television, newspaper articles, popular literature, formal interviews, informal discussions and pilot studies (Watts & Stenner, 2005).

There are two main types of concourse development, the naturalistic and the ready-made (McKeown & Thomas, 1988). A naturalistic concourse uses qualitative interviews with research participants for collection of statements, that is, participants are involved in both the development and the sorting of the statements (McKeown & Thomas, 1988). A quasi-naturalistic concourse draws statements from qualitative interviews with individuals who will not participate in the sorting of the statements (McKeown & Thomas, 1988). Ready-made concourses are not drawn from interviews but rely on additional widely available sources e.g. literature and television sources (McKeown & Thomas, 1988). A hybrid method which involves a

combination of both naturalistic and ready-made sources can also be used (McKeown & Thomas, 1988).

In concourse development it is aimed to collect approximately two to three times as many statements as are actually required for the final set of statements to be used in the Q-sort (McKeown & Thomas, 1988; Watts & Stenner, 2005).

3.2.3.2 Q-set selection

The *Q-set* is a sub-set of statements, systematically selected from the entire concourse, to be used in the Q-sort (Watts & Stenner, 2005). It is necessary to select a sub-set of statements as it would be unfeasible for participants to sort all statements within the concourse due to the large number. Therefore the Q-set aims to broadly represent the range of statements within the concourse (McKeown & Thomas, 1988; Watts & Stenner, 2005). To achieve this, the Q-set should consist of statements which each express a different point of view about the topic of interest (Watts & Stenner, 2005).

How the statements for the *Q-set* are selected is very important. Initially the concourse should be organised and then the statements selected. The two main approaches to the organisation of concourses are unstructured and structured (McKeown & Thomas, 1988). An unstructured Q-set selects statements relevant to the topic of interest from the concourse but does not attempt to cover all possible categories. Such a design has limitations as it may lead to relevant issues being overlooked (McKeown & Thomas, 1988). A structured Q-set aims to overcome this limitation by being more comprehensive. There are two possible structured designs: the deductive and

the inductive. A deductive design is based on hypotheses that the researcher sets before collecting the concourse. These hypotheses dictate the categories in which the concourse should be organised (McKeown & Thomas, 1988). An inductive design does not have specific hypotheses but requires the statements within the concourse to be categorised as they are collected (McKeown & Thomas, 1988).

Once the statements within the concourse have been organised a representative sub-set can then be systematically selected. This can be done in a number of ways. Stephenson (1953) illustrates the use of Fisher's method of experimental design for the systematic selection of statements as it allows for a balanced number of statements to be taken from each category. Other researchers describe less objective methods whereby a process of piloting and reduction by professionals and/or members of the participant group occur (Watts & Stenner, 2005).

There is no general consensus regarding the number of statements that there should be within a *Q-set*. The main considerations when deciding the number are that it is adequate to provide coverage of the area of interest and that the number does not overwhelm the participants (Watts & Stenner, 2005). Recommendations for sizes of Q-sets range from between 40 and 80 statements (Stainton Rogers, 1995; Watts & Stenner, 2005).

However the Q-set is constructed, it can never be seen as completely comprehensive, as it cannot be assumed that all potential viewpoints are sampled (Watts & Stenner, 2005). However, it has been suggested that any participant will attempt to impose their view point on any set of statements

they are given (Watts & Stenner, 2005). As such, even a less than perfect Q-set will produce useful results (Stainton Rogers, 1995; Watts & Stenner, 2005). Therefore, if a Q-set is broadly representative of the topic of interest it should be sufficient to provide a general overview of viewpoints, which is seen as all that is necessary for a Q-methodological study (Watts & Stenner, 2005).

3.2.3.3 Participant selection

The sampling of participants in a Q-methodological study very much depends on the research question. For instance if the study has been designed to determine views on a particular topic then the sampling will be *extensive*, with each individual asked to sort the statements under the same conditions of instruction (McKeown & Thomas, 1988). If the study is focussed at the intra-personal level the sampling will be *intensive*; most likely a single-case where the individual is asked to sort the statements under a variety of different conditions of instruction (McKeown & Thomas, 1988).

In *extensive* samples participants may be selected as a result of pragmatics or through theoretical or strategic sampling (McKeown & Thomas, 1988; Watts & Stenner, 2005). In *theoretical* sampling attempts may be made to select people who are likely to hold different opinions on the topic of interest, in order to maximise the range of alternative viewpoints described (McKeown & Thomas, 1988). However, practical limitations such as the availability of potential participants, motivation to participate, and the ethics of sampling certain populations may not make this possible and a sample may be chosen on feasibility (McKeown & Thomas, 1988). Indeed in Q-methodological studies which are of a truly exploratory nature, this may be the desired

position as rather than the researcher categorising people herself, she wants people to categorise themselves through the Q-sort (Watts & Stenner, 2005).

Q-methodology does not aim to gain a representative view of the topic of interest, instead it aims to identify and describe the range of alternative viewpoints (Curt, 1994). With too many participants the researcher risks the possibility of diminishing the qualities within the data (Watts & Stenner, 2005), however, with two few participants the full range of viewpoints may not be adequately covered (Stainton Rogers, 1995). Therefore, large samples are not required for a Q-methodological study. A rough guide of half as many participants as there are statements in the Q-set is suggested as sufficient for allowing the main viewpoints around the topic of interest to be revealed while maintaining the qualities within the data (Watts & Stenner, 2005). A larger number of between 40 and 60 participants is suggested for publication of Q-methodological studies (Stainton Rogers, 1995; Watts & Stenner, 2005).

3.2.3.4 Q-sorting procedure

As previously discussed the *Q-sort* is one of the main techniques of Q-methodology. It is a method of capturing and representing an individual's point of view about a topic, through their sorting of the Q-set statements (McKeown & Thomas, 1988).

Initially the participant is provided with the Q-set statements in a random order, each on an individual piece of card (Brown, 1993). They are then given a set of *conditions of instruction* which outline how the statements should be sorted, that is, 'sort the items according to those with which you most agree

through to those which you most disagree' (McKeown & Thomas, 1988). To facilitate the sorting, a Q-sort grid is used (See Figure 3.1 for an example). The grid provides the participant with a continuum along which to sort the statements, and specifies the number of statements that should be allocated to each point on the continuum. In Figure 3.1 the numbers in the top line represent the continuum along which the participants must sort the statements. In the bottom square of each column is the number of statements that can be allocated to that continuum point.

Most disagree **Most agree**

- 5	- 4	- 3	- 2	- 1	0	+ 1	+ 2	+ 3	+ 4	+ 5
3										3
	4	4						4	4	
			5				5			
				6		6				
					7					

Figure 3.1: An example of a Fixed Quasi-Normal Distribution Q-sort diagram for a Q-set of 51 statements.

As is illustrated in Figure 3.1 the most common Q-sort grid is a fixed quasi-normal distribution (Watts & Stenner, 2005). The distribution is symmetrical around the mid-point, and is normally flatter than a normal distribution (Brown, 1993). In such a distribution the participants are 'forced' to sort the statements as the grid dictates. However, it is also possible to let the participants sort the statements in a free distribution, where they can assign any number of statements to any point on the scale as such giving the participants greater control (Watts & Stenner, 2005). However, it appears that there is limited benefit from using a free-distribution as it has been established that the impact of the shape of the distribution is negligible, with

little difference in outcome being found at the Q-factor analysis stage (Brown, 1980; Brown, 1993; Watts & Stenner, 2005). In order to support participants in the sorting process a fixed distribution is most commonly used (Watts & Stenner, 2005).

To complete the Q-sort the participant is asked to allocate each statement to a separate position within the grid, leading to each participant producing their own unique model of their understanding of the entire Q-set (McKeown & Thomas, 1988; Stephenson, 1953; Watts & Stenner, 2005). The definitions of the statements are not assumed before they are sorted, but are inferred from the location of the statements following the participant completing the Q-sort (McKeown & Thomas, 1988). If the participant is satisfied with their statement allocation then their sort and each item location is recorded (Watts & Stenner, 2005).

In addition to completing the Q-sort the participant is asked a number of open-ended questions regarding his sort. This is to gather further qualitative information regarding how he has sorted the statements. This information is then used in the analysis and interpretation stage of the Q-methodological study. This information can be collected in a number of ways including a post-sorting interview or questionnaire, or through the use of a response booklet which includes all the statements and space to write comments (Watts & Stenner, 2005).

3.2.3.5 Q-factor analysis and factor interpretation

As discussed earlier Q-factor analysis is the second main technique in Q-methodology and is the mathematical means by which the individual Q-sorts

are compared and groupings of individuals who have sorted the statements in a similar way identified as factors (McKeown & Thomas, 1988). The allocation of each statement to a point on a continuum in the Q-sorting process provides each statement with a numerical value, for instance, the two statements most agreed with and allocated to +5 will each have the value +5. These numerical values are then used to complete the factor analysis (McKeown & Thomas, 1988).

The aim of the first stage of the Q-factor analysis is to identify agreements and disagreements in the viewpoints represented by the participants through their unique Q-sorts (Van Exel & de Graaf, 2005). This is done by looking for correlations between entire Q-sorts (McKeown & Thomas, 1988; Watts & Stenner, 2005), and involves producing a correlation matrix that represents the relationship of every Q-sort with every other Q-sort (not the relationship of each statement with every other statement) (Watts & Stenner, 2005).

As outlined earlier, unlike conventional factor analysis, Q-factor analysis correlates and factor-analyses *people* and not individual items or tests (McKeown & Thomas, 1988). Therefore in the second stage the aim is the extraction of distinct factors through the identification of groupings of highly correlated Q-sorts, each factor should include individuals who have sorted the statements in a similar way and share similar viewpoints about the topic of interest (Van Exel & de Graaf, 2005; Watts & Stenner, 2005). The factors are extracted through the factor analysis of the correlation matrix (Watts & Stenner, 2005). There are two main methods of factor analysis available to the Q-methodologist:

- **Centroid**: the centroid method of factor extraction is often preferred by Q-methodology researchers (and by Stephenson himself) as it offers an infinite number of possible rotated solutions, allowing for judgemental rotation and gives the researcher control over selecting which rotated solution they feel is the most appropriate and theoretically informative (McKeown & Thomas, 1988; Watts & Stenner, 2005).
- **Principal components analysis (PCA)**: more recently researchers have been turning to the PCA method as it automatically seeks the fewest number of factors which can account for the common variance of a set of variables (Watts & Stenner, 2005).

The researcher must consider what method is most appropriate to meet the aims of their specific study, however, the difference between the two methods has been found to be negligible (McKeown & Thomas, 1988; Watts & Stenner, 2005).

The third stage is deciding how many factors to take forward to factor rotation and interpretation following the completion of the initial factor analysis (Van Exel & de Graaf, 2005). Two criteria must be met by the factor for it to be considered;

- The factor must have an eigenvalue greater than 1.00, to maintain reliability of factors (McKeown & Thomas, 1988; Watts & Stenner, 2005).
- At least **two** Q-sorts must load significantly upon the factor (Watts & Stenner, 2005).

However, factors may be found which although statistically significant hold very little theoretical meaning while factors which are statistically non-

significant yet theoretically interesting may be overlooked (McKeown & Thomas, 1988). Both theoretical and statistical importance must therefore be considered when extracting factors (McKeown & Thomas, 1988).

The fourth stage is the rotation of the selected factors to produce a final set of factors (Van Exel & de Graaf, 2005). There are two main methods of rotation;

- **Judgemental**: this method of rotation gives more control to the researcher who can subjectively determine which rotation he selects based upon his aims, theoretical concerns, or ideas that came up during the study (Van Exel & de Graaf, 2005).
- **Varimax**: the varimax method is increasingly commonly used in Q-studies due to its simplicity and reliability (McKeown & Thomas, 1988; Watts & Stenner, 2005). It is seen as objective as the rotation is determined by the structures of the data (Van Exel & de Graaf, 2005). It maximises the amount of variance explained by the extracted factors (Brown, 1980; Watts & Stenner, 2005).

The technique of rotation that is chosen for the factor analysis should be decided upon on the basis of the aims of the research and the types of data that have been collected (Brown, 1980; Watts & Stenner, 2005). Following factor rotation a factor loading is calculated that represents the strength with which each Q-sort loads onto a factor (Donner, 2001).

The fifth stage is the identifying of Q-sorts which exemplify each factor, these are called *factor exemplars*. A factor exemplar is a Q-sort that loads cleanly and significantly onto only one factor (Watts & Stenner, 2005). The more a Q-sort loads cleanly onto a factor the better that factor describes the viewpoint represented in the Q-sort (Donner, 2001). Significance is determined by

examining the strength with which the Q-sort loads onto the factor, the level at which significance can be determined varies but $p>0.45$ is believed to be a rigorous level (Stephenson, 1953). The factor exemplars for each factor are then combined to produce a best-estimate Q-sort that characterises that factor (Watts & Stenner, 2005). To produce the best-estimate Q-sort for each factor, the individual loadings of each exemplifying Q-sort onto a factor are used to establish their contribution to the best-estimate (Watts Stenner, 2005). It is these best-estimate Q-sorts or factor arrays which are interpreted (Watts & Stenner, 2005).

There are various dedicated statistical packages available which carry out all stages of the Q-factor analysis described above, these include PCQ for windows (Stricklin & Almeida, 2001) and PQ Method (Schmlock, 2002). PQmethod (Schmolk, 2002) is free to download from the internet, is easy to use and presents the results of the analysis in an accessible form.

Finally, following the completion of the Q-factor analysis the interpretation of the extracted factors, and their associated best-estimate Q-sort, can begin. In interpretation the aim is to produce summaries of each factor. Each summary should make clear the view points that are being expressed by the individuals that load on each particular factor (Watts & Stenner, 2005). This can be done by considering the statements which have been most strongly agreed or disagreed with (e.g. +5/-5) by all the participants grouped in the factor, while also making comparisons between factors (Watts & Stenner, 2005). However, so as not to lose the holistic viewpoint held by the individuals grouped in each factor, it is important to consider as broadly as possible the entire best-estimate Q-sort (Watts & Stenner, 2005). The

dedicated statistical packages automatically identify *distinguishing* statements and *consensus* statements which are useful for factor interpretation. Distinguishing statements are statements which are ranked significantly differently by those exemplifying a factor from their ranking in other factors (Donner, 2001). Consensus statements are statements which are not ranked differently and therefore do not distinguish between any factors (Donner, 2001). Interpretations can be clarified and validated using the additional qualitative information gathered from Q-sort and further description of the factor can be gained by considering the demographics of the individuals that exemplify each factor (Watts & Stenner, 2005). A further possibility for ensuring the efficacy of the interpretations is to present them to those participants who have significantly loaded on the factors for comment (Stenner & Watts, 2005).

3.3 Advantages of Q-methodology

Q-methodology provided a number of advantages for this study, these will be outlined below.

3.3.1 An exploratory technique

Q-methodology was developed by William Stevenson, as an exploratory technique (Watts & Stenner, 2005). Qualitative methodologies on the whole are designed to be exploratory and identify themes within individual's narratives, so one could dispute this as not being an advantage specific to Q-methodology. However, where Q-methodology advances is that it allows the exploration of the combination and configuration of themes that have been identified (Watts & Stenner, 2005). Such a technique is compatible with the aims of the study, to explore the range of alternative viewpoints of

Asperger's Syndrome and High Functioning Autism. In similar studies Q-methodology has been used to explore the understanding of the experience of hearing voices (Jones *et al*., 2003) and the experience of neuroleptic medication in patients with schizophrenia (Day *et al*., 1996).

3.3.2 Focus on the subjective

Q-methodology allows the researcher to systematically examine people's points of view on matters of personal significance, for instance their subjective understanding (McKeown & Thomas, 1988). This approach is consistent with the aim of the research, which is to explore the range of alternative subjective understandings of Asperger's Syndrome and High Functioning Autism.

3.3.3 Small sample sizes

Q-methodology is designed to be used with small sample sizes, indeed larger Q-methodological studies run the risk of diminishing the qualities within the data (McKeown & Thomas, 1988; Watts & Stenner, 2005). As the potential population of participants available for this study is not large and may also be relatively inaccessible, it is an advantage that the methodology can be rigorous with smaller numbers (Thomas & McKeown, 1988).

3.3.4 Visual and structured format

The Q-sort involves the use of visually presented material. It is highly structured and each participant must follow the same set of instructions (McKeown & Thomas, 1988). People with Asperger's Syndrome and High Functioning Autism can have difficulties with verbal communication and may rely on structure to support them when completing activities (Attwood,

1998). Consequently, the structure and visual format of a Q-methodological study appear appropriate for use with individuals with Asperger's Syndrome or High Functioning Autism. Indeed providing a visual structure by which individuals can organise their subjective experience may give Q-methodology advantages over other qualitative methodologies for this population.

3.3.5 Bridge to future quantitative analysis

Q-methodology makes use of qualitative knowledge and discourse around a topic of interest and builds upon this knowledge, allowing the extraction of the range of alternative understandings within the population as distinct factors. These distinct factors provide a platform from which specific hypotheses can be built to bridge the gap to larger scale quantitative analysis and experimental study (Stephenson, 1953; McKeown & Thomas, 1988). Such an approach is a particular advantage to this study where the aim is to build upon the developing qualitative research into the experience of diagnosis in adulthood and to move knowledge forward to a point where questions about potential links between understanding, identity and adjustment can be explored.

3.4 Limitations of Q-methodology

It is important when discussing a methodology to acknowledge its limitations. These are discussed below and where appropriate potential safeguards have been described.

Q-methodology has been criticised for simply taking a few extreme participants and describing their idiosyncrasies (Stevenson, 1953; Watts &

Stenner, 2005). This is a possibility, but is minimised by the careful consideration of participant selection, where researchers attempt to select a wide range of individuals from the relevant population (Watts & Stenner, 2005). Importantly, the probability of the statements being sorted in a similar way by chance is so small that when it does occur and correlations are observed it would suggest that individuals are relating to the statement set in a similar way (Shemmings, 2006; Stephenson, 1953). A further defence against this criticism is to consider the aims of the methodology. The different factors identified through Q-analysis describe the range of alternative viewpoints observed, however, no attempt is made to describe representative views or give greater weight to one particular view over another (Curt, 1994). Additionally, the factors are only the starting point and subsequent interpretations are always made in respect of the additional knowledge that the researcher has regarding the participants (Curt, 1994).

The process of Q-statement selection has been criticised due to the potential for the researcher to impose their own preconceptions (Curt, 1994; Stainton Rogers, 1991). Researchers have defended this criticism by acknowledging that indeed the outcome of the study may be constrained by a poorly constructed Q-set but not by the researchers' preconceptions (Curt, 1994; Stainton Rogers, 1991). It is argued that it is the participants not the researcher that is in control of the factors which appear (Curt, 1994; Stainton Rogers, 1991). This is because for each participant there are a great number of possible configurations they could express, they choose which to express not the researcher (Curt, 1994; Stephenson, 1953). Indeed, this sense of the participants being in control is commonly cited as a key reason why researchers choose Q-methodology (Curt, 1994; Stainton Rogers, 1991).

Additionally, the replicability and generalisability of the findings from Q-methodological studies have been questioned (Stevenson, 1953; Curt, 1994). However, Q-methodology makes no assumption that its findings will be the same if the study is replicated, it is seen as a snap-shot in time (Curt, 1994; Stainton Rogers, 1991).

3.5 Summary

An overview of Q-methodology has been provided including a description of the main techniques (Q-sort, Q-factor analysis) and a detailed discussion of the steps required to complete these techniques. Finally, a number of advantages and limitations of using this methodology relevant to this study were outlined. It was concluded that this methodology was appropriate for meeting the aims of the study. The aims and objectives of the study will be outlined in chapter 4.

CHAPTER 4: Aims and objectives of study.

4.1 Aims and Objectives

The aim of this study was to explore how Asperger's Syndrome and High Functioning Autism were understood by those who had received the diagnosis in adulthood, with particular focus on the range of beliefs and understandings held. The presence of differing beliefs about Asperger's Syndrome and High Functioning Autism and their relative importance to the individual have been hypothesised in previous research as important to the experience of diagnosis and in post-diagnostic identity development (Cousins, 2001; Molloy & Vasil, 2004; Punshon, 2006).

The experience of diagnosis in adulthood, as described in Chapter 2, is relatively unexplored. Tentative investigation of diagnosis in adulthood and adolescence has begun using qualitative methodologies (Cousins, 2001; Molloy & Vasil, 2006; Punshon, 2006). These few studies, although focussed upon the entire diagnostic experience, have started to describe the understandings and beliefs adults hold about their diagnosis. Broadly all the studies indicated how Asperger's Syndrome and High Functioning Autism were conceptualised as either a deficit, difference or advantage. However, the range of alternative viewpoints and the specifics of the beliefs incorporated within these viewpoints were not clear. It was felt that building upon the current understanding was essential, particularly with a view to increasing the depth of current knowledge and guiding clinical practice.

Q-methodology was identified by the author as an appropriate methodology to meet the aims of the research. The choice of methodology will be evaluated in the discussion.

4.2 Hypotheses

This study is an exploratory study and therefore no specific hypotheses have been outlined.

METHOD SECTION.

The study was conducted in two phases. Chapter 5 will discuss phase one, the development of the statement set. Chapter 6 will discuss phase two, the completion of the Q-sort and subsequent analysis and interpretation.

CHAPTER 5: Statement Development

The first phase of the study involves the development of the *Q-set*. As described in Chapter 3 the *Q-set* is a set of statements, which is broadly representative of the points of view, beliefs, understandings and opinions contained within the entire *concourse* that surrounds the topic of interest (Stainton Rogers, 1991; Watts & Stenner, 2005). Therefore, in phase one of the study there were two stages, firstly the entire *concourse* was collected and secondly, the *Q-set* statements were systematically selected from it. Both stages will be discussed in turn below.

5.1 Ethical and Research and Development Approval

As the study was a research project involving contact with service users it was essential that it be evaluated by a Research and Ethics Committee (REC) and by the relevant Research and Development (R&D) departments for all the anticipated sites of data collection.

An ethics proposal was completed and submitted to the local Research and Ethics Committee. This REC has the capacity to evaluate multi-site studies. The author attended a meeting with all the REC members where the study was discussed and required amendments outlined (see Appendix 5.1 for full amendments). An important amendment was that any favourable opinion given at this stage would be contingent on the REC reviewing and approving the Q-set before the author could continue onto the second phase of the study. The amendments were addressed and re-submitted to the REC who subsequently gave approval for the study to commence (See Appendix 5.2).

The study ensured the maintenance of confidentiality and anonymity throughout all stages including recruitment, participation, storage of data and write-up, which is consistent with good practice guidelines for research (British Psychological Society, 2004). Recruitment involved contacting individuals diagnosed by the locality diagnostic service in the past two years. The author is a member of the locality diagnostic service and therefore has a clinical role within the service giving access to patient data, such access does not breach data protection and was approved by the diagnostic service and the ethics committee and is consistent with good practice guidelines (British Psychological Society, 2004).

Additionally, for this study particular consideration of additional ethical issues was paramount due to the potential vulnerability of the participant group and the associated communication difficulties individuals may experience. To safeguard against potential difficulties it was ensured that participants were aware they could stop and take breaks at any time or end participation, and that if they found any statements distressing this could be discussed. Additionally all the written and verbal information was carefully considered and reviewed and comprehension checked.

5.2 Concourse collection

The concourse is the foundation of a Q-methodological study, the comprehensiveness of the concourse influences the ability of the study to generate worthwhile data (Curt, 1994). To establish comprehensiveness it was aimed to gather current understandings and communications, regarding the understanding of Asperger's Syndrome and High Functioning Autism in adults, from a wide range of sources.

5.2.1 Design

To establish a concourse that was as comprehensive as possible within the time limitations of the study, it was decided that a quasi-naturalistic hybrid concourse would be developed (McKeown & Thomas, 1988). Such a concourse is hybrid as it involves sourcing beliefs and opinions from both ready-made sources (e.g. media, academic literature) and from naturalistic sources (e.g. interviews with individuals with Asperger's Syndrome or High Functioning Autism), and it is quasi-naturalistic as the individuals involved in the interviews would not be participating in the Q-sorting process (McKeown & Thomas, 1988). The following sources of information were identified. The first two are quasi-naturalistic sources while the remaining four are ready-made sources;

a) Focus group with individuals with a diagnosis of Asperger's Syndrome or High Functioning Autism.

b) Focus group with professional members of the locality diagnostic service.

c) Current understanding in academic literature (e.g. medical, psychological, social, educational literature).

d) Published autobiographical accounts of diagnosis.

e) Relevant online resources (e.g. support websites).

f) Relevant media representations (e.g. newspapers, television or radio programmes).

In many Q-methodological studies the concourse has been collected through relying heavily on semi-structured interviews completed with individuals or groups of individuals relevant to the topic of interest (Bryant *et al*., 2006;

Jones *et al*., 2003; Lister & Gardner, 2006). The author would have liked to have conducted a wider range of interviews, however this was not deemed to be possible within this study for two reasons:

- The time constraints of the study limited the length of time that could be spent on phase one without compromising phase two.
- The size of the potential participant population is relatively small and of increasing interest to researchers. As such the researcher felt that participants should only be recruited for one phase of the study, therefore to ensure adequate participants were available for phase two a limited number were sampled in phase one.

It was hoped that the use of autobiographical accounts, media accounts and online resources would provide communications of a similar quality to those taken from interview sources in previous studies. There is an increasing volume of online accounts of diagnosis open to public access which provide subjective explanations of the experience of diagnosis.

5.2.2 Procedure

Separate procedures were used for collecting statements from each different source type. Each procedure will be discussed separately below. However, for all procedures the actual extraction of statements was the same, for instance, statements were selected on the basis of their potentiality as an answer to the following question, *'What does it mean to receive a diagnosis of Asperger's Syndrome or High Functioning Autism as an adult?'*. The question was understood by the author in its broadest form, incorporating not only what it means to receive a diagnosis but how is Asperger's Syndrome or

High Functioning Autism understood by those who receive a diagnosis in adulthood?

Statement selection attempted to maintain diversity and prevent the narrowing of the concourse (Stephenson, 1953). In the initial stages of the statement collection a loose structure began to emerge and for ease of recording the statements were grouped accordingly. The groupings included reaction to diagnosis, impact on quality of life, theories for understanding Asperger's Syndrome or High Functioning Autism, associated strengths and difficulties, and 'other' for all those statements that appeared not to fit elsewhere.

Each statement identified was taken verbatim from the text[3] and entered into an excel database. The source of the statement was also recorded to allow for verification. The author was responsible for the selection and extraction of the statements for the concourse, however, the entire statement list was presented to both the academic and clinical supervisors for consideration. The entire concourse, including references is included in Appendix 5.3.

5.2.2.1 Focus Group with people with a diagnosis of AS or HFA

As discussed earlier interview data is a very useful tool when collecting the concourse. It was hoped that by using focus groups rather than individual interviews it would allow the collection of a wider range of view points within a shorter time frame.

5.2.2.1.1 Participants

[3] Any identifiable information within the statements was omitted; if this significantly disrupted the meaning of any statement then it was discarded altogether.

Convenience sampling was used to recruit participants for the focus group. All participants were recruited from a support group for adults with Asperger's Syndrome or High Functioning Autism. The support group incorporated individuals who had not received a formal diagnosis but who had self-diagnosed. As outlined earlier the number of individuals diagnosed with Asperger's Syndrome or High Functioning Autism in adulthood is relatively small. To preserve numbers for phase two of the study the author made the decision to include individuals who had not been formally diagnosed in the focus group. The author acknowledges that this decision was not ideal due to the possibility that it could lead to an over emphasis on positive viewpoints of Asperger's Syndrome and High Functioning Autism[4].

Six individuals participated in the focus group, with all but one of the participants being male. The mean age was 43.5 years (SD = 13.4 years). Three participants reported having received a formal diagnosis of Asperger's Syndrome, and three reported that they had self-diagnosed and were living as if formally diagnosed[5]. All participants were able to give informed consent to participate.

5.2.2.1.2 Design

A focus group is a way of collecting qualitative data, by engaging a small group of adults in an informal group discussion, which is 'focused' on a particular topic (Stewart *et al*., 2007; Wilkinson, 2003). It has become a more popular method of data collection with the increasing interest in qualitative

[4] It could be hypothesised that those individuals who voluntarily self-diagnose themselves will identify strongly with the positive characteristics of Asperger's Syndrome and High Functioning Autism.

[5] The author was not able to gain independent verification of the diagnosis and had to rely on the self-report of the individuals. There is obviously the possibility that individuals gave false declaration of diagnosis, however, this was felt to be unlikely by the author.

methodologies (Wilkinson, 2003). Focus groups can be used as part of mixed-methodology (Wilkinson, 2003), and they have been used as sources for the development of the concourse in previous Q-methodological studies (McKeown & Thomas, 1988).

Focus groups are dynamic and allow for debate, discussion and disagreement (Wilkinson, 2003), which can lead to the researcher gaining a range of different points of view and positions. The number of participants in a focus group normally ranges between 4 and 12 (Stewart *et al.*, 2007; Wilkinson, 2003). Focus groups can involve groups of individuals who are already known to each other, or it can bring together a range of individuals for a variety of purposes (Wilkinson, 2003). A typical focus group lasts between 1.5 and 2.5 hours (Stewart *et al.*, 2007). The group facilitator ensures that the discussion remains on topic, but can be nondirective, letting the discussion continue as long as it stays on task (Stewart *et al.*, 2007).

This focus group was designed to meet on one occasion and to bring together a group of adults who were already known to each other. These individuals were selected as they were all members of a support group for adults with Asperger's Syndrome or High Functioning Autism. It was decided that as the group of individuals had never participated in a focus group previously it would be appropriate to limit the group to one hour, so as not to overwhelm or distress people. A question outline sheet was constructed (see Appendix 5.4), this was kept brief and was designed to give answers to the broad question 'What does it mean to receive a diagnosis of AS/HFA as an adult?'. The questions were:

- What does having AS/HFA mean to you?

- How do you feel about having AS/HFA?
- Are there positive aspects of having AS/HFA?
- Are there negative aspects of having AS/HFA?
- Are there any areas of your life that having AS/HFA impacts upon?

5.2.2.1.3 Procedure

The recruitment process was guided by and carried out in agreement with the support group leader. The author was known to the group, as in the development stages of the research project she had attended a group meeting to obtain feedback on potential research ideas. The recruitment process involved a short presentation and discussion by the author, which was held at the group's monthly meeting. All group members were provided with contact details for the author[6] so they could request further information regarding participation in the study. Four potential participants contacted the author by email.

When contacted the author sent out the participant information sheet for the focus group (see Appendix 5.5 for information sheet and consent form) and a copy of the focus group interview guide[7]. A convenient time was made to meet with each individual to discuss the sheet. It was not possible to arrange a time to meet face-to-face with two participants as they both worked full time and so a telephone discussion was arranged to discuss the sheet and provide the opportunity for potential participants to ask questions. Additionally, one potential participant had raised a query regarding equity of access to participation for those individuals who perhaps were unable to access the internet and had difficulty using the telephone. To address this,

[6] Mailing address, email address and telephone number.
[7] When the author gave the presentation to the group, they all requested that they could see the questions prior to participating so that they could prepare and know what to expect.

the author organised a drop-in session. The details of this were communicated to potential participants by the group leader. An additional two individuals attended this way and were provided with an information sheet. All participants were given at least 48 hours before being contacted regarding whether they wished to participate.

All six individuals who had requested the participant information sheet agreed to participate, and a convenient location and time was arranged. The focus group took place in the building in which the support group usually occurred, which was safe and familiar to participants. Written consent was taken from the participants prior to the focus group starting. Once consent had been taken the author gave a summary of the research and the purpose of the focus group, the procedure for the group was reiterated, ground rules were set, and there was time for questions. Following this the group was encouraged to participate in a warm up exercise which they normally used prior to their meetings.

Once all members were relaxed and comfortable, the author switched on the digital recorder and asked the first question on the focus group question sheet. Throughout the session the author facilitated the discussion, by ensuring that all participants had an opportunity to discuss and by maintaining the focus on the questions (c.f. Stewart *et al.*, 2007; Wilkinson, 2003). The focus group lasted for 68 minutes, and there was time following this for summary and debrief.

The focus group was recorded and transcribed by the author (see Appendix 5.6 for an excerpt of the transcription). Statements were selected directly

from the transcripts and entered into the concourse database (Appendix 5.3), confidentiality and anonymity of the statements was maintained.

5.2.2.2 Focus Group with professional members of the RASDCS

Unfortunately, due to a delay in the establishment of multi-centre Research and Development approval it was not possible to complete the focus group with the professional members of the locality diagnostic service. A decision to omit this source was taken as it was felt that this group of individuals were more likely to express a medical oriented understanding of Asperger's Syndrome and High Functioning Autism, which was already clearly established through the sourcing of the academic literature.

5.2.2.3 Sourcing of academic literature

The academic search engines PSYCINFO[8], MEDLINE[9] and EMBASE[10] were used for searches and accessed through the OVID system[11]. The following search terms were used Asperger's Syndrome; Asperger's Syndrome AND adjustment; High Functioning Autism; High Functioning Autism AND adjustment; Autism Spectrum Disorder; Autism Spectrum Disorder AND Adjustment; Autism and Adult; Autism AND adjustment. The following criteria were used to select relevant papers (Table 5.1 indicates the number of papers identified);

- Relating to Asperger's Syndrome or High Functioning Autism.
- Relating to diagnosis.

[8] Searched papers stored from 1806 to Week 3 December 2007
[9] Searched papers stored from 1980 to Week 1 January 2008
[10] Searched papers stored from 1950 to Week 1 January 2008, additionally OVID MEDLINE (R) In process and other non-indexed citations and OVID MEDLINE (R).
[11] The following search codes were used, English language only; keyword anywhere; human; remove duplicates.

- Relating to teenagers and/or adults (although if a paper from child literature relevant then it was selected).
- Includes discussion of following topics;
    - Subjective understanding and/or meanings of Asperger's Syndrome or High Functioning Autism,
    - Beliefs about Asperger's Syndrome or High Functioning Autism,
    - Current theoretical understanding of Asperger's Syndrome or High Functioning Autism,
    - Impact on quality of life.

Table 5.1: A table indicating the number of academic papers identified, selected and reviewed for each search term.

Search term	*Total number of papers*[12]	*Total number of papers selected*
AS	1552	251
AS & adjustment	40	40
HFA	393	63
HFA & Adjustment	11	3
ASD	632	26
ASD & adjustment	19	4
Autism & adult	3129	136
Autism & adjustment	422	31

The abstracts of all the papers selected were read by the author, if the paper was deemed relevant then it was read in more depth. Any relevant statements identified were selected and added to the excel database (Appendix 5.3).

5.2.2.4 Sourcing of autobiographical accounts

A number of autobiographical accounts of diagnosis were reviewed. These accounts were selected initially through their inclusion on online lists[13] of

[12] After application of search codes e.g. removal of duplicates

books relating to personal accounts of diagnosis of Asperger's Syndrome or High Functioning Autism in adulthood. The final accounts selected were chosen based on their relevance to the experience of diagnosis in adulthood (e.g. Birch, 2003; Holliday Willey, 1999; Mitchell, 2005; Murray, 2006; Purkis, 2006).

The books were read by the author and statements selected and added to the excel database (Appendix 5.3).

5.2.2.5 Sourcing of online and media representations

To sample the vast array of internet resources a number of specific search criteria were established. All the online searches were conducted using the Google search engine, and four searches were conducted using the following terms: Asperger's Syndrome; Asperger's Syndrome AND adult; High Functioning Autism; High Functioning Autism AND adult. For each search term the top fifty websites were considered, and selected if they met the following criteria;

- Websites only, all books and journal articles omitted
- Relating to Asperger's Syndrome or High Functioning Autism (or autism if also discussing Asperger's Syndrome or High Functioning Autism)
- Discusses implications for those diagnosed in adulthood
- Written by adults describing personal experiences
- Not a repeated site (e.g. different page on site already listed)

[13] Compiled by individuals with AS/HFA and posted on a popular online book store.

The online resources included self-help websites for families and for individuals with Asperger's Syndrome or High Functioning Autism; personal websites of individuals with Asperger's Syndrome or High Functioning Autism; online news articles; YouTube videos posted by individuals with Asperger's Syndrome or High Functioning Autism; personal accounts of diagnosis; and Wikipedia sites. The number of websites considered is outlined in Table 5.2 and the individual site listings are available in Appendix 5.7. Additionally links to other websites accessed through the selected sites were reviewed if they also met the criteria.

The media samples were also accessed through the internet, with articles being selected from a number of online newspaper archives and from the BBC news website. Statements were taken directly from both the online and media sources and added to the excel database (Appendix 5.3).

Table 5.2: A breakdown of the number of websites selected following online searches and those accessed.

Search Term	*Number of Websites selected.*	*Number of websites accessed.*
Aspergers Syndrome	17	14
Aspergers Syndrome & adult	8	7
High Functioning Autism	9	7
High Functioning Autism & adult	4	4

5.3 Q-set selection

5.3.1 Design

The final concourse totalled 305 items (see Appendix 5.3). Although no concourse can assume to be exhaustive (Watts & Stenner, 2005), it was hoped that the processes involved in the collection of the concourse led to a reasonably comprehensive coverage of the current understanding of

Asperger's Syndrome and High Functioning Autism and their diagnosis in adulthood.

The process of reduction needs to be rigorous and systematic to maintain reliability, and to ensure that the statements represent a range of points of view (Stainton Rogers, 1991). The process of reduction was completed with the support of a young female with Asperger's Syndrome who acted as a co-researcher throughout this process. It was hoped that by having a member of the user group involved in the process it would add validity to the statement selection and provide an opportunity for the establishment of readability and comprehensibility. It was also felt to be a very interesting and informative part of the research process, as the co-researcher continued to support the research process throughout by providing active discussion around the research area. Involving the user group in this part of the process is outlined in the process of 'piloting' used to reduce the statements to produce a broadly representative Q-set (Watts & Stenner, 2005). Additionally both the clinical and academic supervisors along with the author were involved in the statement reduction process.

A number of important considerations when selecting the Q-set have been outlined by Watts and Stenner (2005);

- Avoidance of semantic duplication
- Statements are clearly expressed using everyday non-technical language, avoiding ambiguity (Stainton Rogers, 1991)
- Statements express a single proposition only
- Q-set provides a balance of positively and negatively valanced statements

It is essential for Q-methodological studies that the statement set used has an equal balance of positive and negative statements, to facilitate the sorting process and reduce potential bias resulting from the piling up of statements on either the positive or negative side of the Q-sort diagram (Brown, 1997). Once the statements have been selected they should all be presented in the present tense and from a self-referential position (McKeown & Thomas, 1988).

5.3.2 Procedure

It has been suggested that the concourse should be approximately three times the size of the desired Q-set (Stainton Rogers, 1991), for this study it was aimed for the Q-set to be between 40 and 60 statements which is consistent with reputable studies utilising a Q-methodology (Bryant *et al.*, 2006; Jones *et al.*, 2003). The full concourse of 305 statements was five times the size of the desired final Q-set.

The first stage of the refinement of the concourse was the categorisation of the statements within it. Although the statements were initially collected within the categories listed above[14] category statement selection was data driven. This meant that all statements were considered together and new categories of statements were extracted, as has been the practice in previous studies (Bryant *et al.*, 2006). The process of extracting categories was completed by the author, the full concourse was considered together and statements believed to be expressing similar viewpoints were grouped. This process resulted in the extraction of 20 categories. These categories were then reviewed by the clinical and academic supervisors, and by the co-researcher

[14] Reaction to diagnosis; impact on Quality of Life; theories for understanding AS/HFA; associated strengths and difficulties; other.

with Asperger's Syndrome. They were instructed to consider whether they believed the groupings of statements, extracted by the author, represented distinct viewpoints. The aim of this was to establish agreement and face validity for the categories extracted. They supported the categories extracted.

Once the categories had been agreed upon all 305 statements were considered, and 70 statements removed as they duplicated other statements, or they were expressed in language deemed too idiosyncratic or unclear.

The remaining 235 statements were distributed to the academic and clinical supervisors, the co-researcher with Asperger's Syndrome and the author. All were instructed to select between 40 and 60 statements which they felt represented the complete statement set. As a guide the number of statements to be selected from each category was indicated on the selection sheet (see Appendix 5.8). All individuals commented on the difficulty of selecting statements, with it being necessary to make a conscious effort to remain objective and not be influenced by their own personal subjective opinion.

Concordance between raters was looked for and as such the 52 statements that received no selections were removed, leaving a statement set of 183. A further 12 statements were removed by the author[15], reducing the total number of potential statements to 171. Conversely all statements which received three or more selections were identified. There were 7 statements with complete concordance and 22 statements with partial concordance. The

[15]These were statements that the author had marked as possibilities but had not specifically selected. This was to allow the author to consider them again once all the raters selections had been collected to view any concordance. As there was no concordance these statements were immediately discarded.

statement list was considered again by the author and **c**linical Supervisor, and a further 33 statements were selected to give 52 statements.

All selected statements were checked for tense and self-referential focus, with a number of statements re-worded to be self-referential and in the present tense while retaining their original meaning. Additionally, a number of statements were shortened, as their double-barrelled form was felt to be out of line with the other statements and may lead to confusion at both the sorting and interpretation stages. The final statement list was then reviewed to check comprehensibility, readability and balance of positive and negative statements by the academic and clinical supervisors, the co-researcher with Asperger's Syndrome and two additional **c**linical psychologists[16]. The final statement list can be viewed in Appendix 5.9.

5.4 Summary

Phase one of the study, the process of statement development, has been described. Chapter 6 will describe phase two, the Q-sorting procedure.

[16] These individuals were not knowledgeable about the study.

CHAPTER 6: Q-sorting and analysis

The second phase of the study involved the completion of the Q-sorting procedure and the subsequent correlation and Q-factor analysis of the completed Q-sorts.

6.1 Ethical Approval

As outlined in chapter 4 the ethical approval awarded to the study was contingent on the completed Q-statement set being reviewed by the entire ethics committee before recruitment for the second phase of the study. The completed set was duly submitted and the ethics committee reviewed the statements, they noted nothing of concern and gave permission for the second phase of the study to commence.

6.2 Q-sorting

Q-sorting is an active process whereby the participant engages with the Q-set statements and sorts them based on their relative agreement and disagreement with each statement (Brown, 1997; Stephenson, 1953; Watts & Stenner, 2005). The final result is a Q-sort or model which is specific to each individual.

6.2.1 Participants

All participants in the second phase of the study were adults (+ 18) with a formal diagnosis of Asperger's Syndrome or High Functioning Autism. All participants had received their diagnosis in adulthood[17]. All participants

[17] For participants not recruited through the locality diagnostic service the researcher relied on self-reports of the participants for verification of their diagnosis. This was not ideal as it increased the potential for inaccuracies i.e. false declaration of diagnosis. However, such

were of average or above average intellectual ability, and had adequate literacy skills to read the participant information, give informed consent and complete the Q-sort task[18]. Table 6.1 outlines the inclusion and exclusion criteria for participation in the study.

Table 6.1: Inclusion and exclusion criteria for participation

Inclusion Criteria	*Exclusion Criteria*
1. A diagnosis of AS and/or HFA received when an adult (18+) **2. Currently aged 18+** **3. Adequate literacy skills to participate in study** **4. Resident in Fife, Lothian, Forth Valley or Borders**	**1.** Accompanying Learning Disability **2.** An inability to give informed consent e.g. as a result of a significant mental health difficulty

All participants gave written informed consent to participate. All participants also gave consent to be contacted to provide feedback on the interpretation of the factors resulting from the factor analysis.

6.2.2 Design

The Q-sorting process followed the conventional design (Curt, 1994; Stainton Rogers, 1991; Stephenson, 1953; Watts & Stenner, 2005). The Q-set statements were presented individually to the participant who was instructed to sort the statements within a Q-sorting grid, to produce an individual Q-sort. This Q-sort could then be represented numerically and along with other sorts subjected to correlation and Q-factor analysis to identify similarities.

false declaration was to some extent safeguarded against as the other recruitment routes were through agencies which required individuals to have a formal diagnosis for access.

[18] For those recruited through the locality diagnostic service information on the presence of an accompanying learning disability was available. For all other recruitment routes this information was not available and cognitive assessment was beyond the scope of the study. The researcher made a judgement at the initial meeting.

6.2.3 Materials

6.2.3.1 Q-set statements

Each Q-set statement was allocated a random number, using an online number randomisation program. This number[19] allowed identification and recording of the position of each statement following completion of the Q-sort, it was also the order in which the statements were initially presented to the participants. Each of the Q-set items was printed onto an individual card (approximately 4cm by 6cm) and laminated.

Additionally all the statements were printed in a booklet with space for comments to be written. Either the participant or the author, dependent on the participant's preference, recorded any comments about the statements the participant made during the sorting process.

6.2.3.2 Q-sort grid

The Q-sort diagram was constructed so that there were 52 available spaces, arranged in a fixed quasi-normal distribution along a continuum rating scale ranging from +5 to -5. Under each rating point a set number of statements can be placed, which is dictated by the shape of the distribution. In this study two statements could be placed under both +5 and -5, three under both +4 and -4, and four under +3 and -3, and so on. The diagram was printed onto A0 laminated card (an A4 version can be seen in Appendix 6.1). Each space on the diagram was the same size as the Q-set cards, and each card and space had a Velcro fastener attached to allow the cards to be fixed to the diagram.

[19] The statement numbers were not presented on the front of the cards as concerns were raised that perhaps individuals would sort the statements based upon this number. They were written on the back to allow rapid recording of statement position on the recording sheet.

A record sheet (identical to the Q-sort diagram shown in Appendix 6.1) was also constructed that allowed the recording of the final position of the statements. It also gave space for recording of the initial numbers of statements that participants indicated they agreed, disagreed or were neutral about.

6.2.3.3 Conditions of instruction

To facilitate the Q-sorting process a set of conditions of instruction was produced, outlining the criteria by which the statements should be sorted. Participants were asked to sort the statements based upon how much they agreed with each statement, ranging from the statements they most agreed with through to those they most disagreed with. The instructions also clearly outlined the individual stages the participant should take to complete the Q-sort. See Appendix 6.2 for a copy of the conditions of instruction.

6.2.3.4 Demographic questionnaire

A short questionnaire was devised to collect information that would be useful for factor interpretation (a complete version is available in Appendix 6.3). The questionnaire collected two types of data;

- Information relating to the experience of completing the Q-sort e.g. rationale for choice of statement at the extremes of the grid, difficulties associated with sorting, and satisfaction with sort.
- Demographic information felt to be pertinent to how a person may understand the diagnosis, was organised into four main areas;
    - Diagnosis (e.g. date of diagnosis, motivation for diagnosis, length of diagnostic process, happiness with diagnosis, previous diagnoses)

- Past experience of mental health difficulties
- Attainment (e.g. education, employment)
- Family (e.g. awareness of diagnosis, support, current living situation, other family members with Autism Spectrum Disorder)

The questionnaire was designed to be conducted as a semi-structured interview administered by the author and to take approximately 15 minutes.

6.2.4 Procedure

6.2.4.1 Recruitment

Participants for the study were recruited from a large geographical area in Scotland, through three main routes;

a) A locality Autism Spectrum Disorder diagnostic service

b) An Autism Spectrum Disorder specific support agency

c) A support group for adults with Asperger's Syndrome

The recruitment process was different for the three routes so all the processes will be outlined below.

a) Locality Autism Spectrum Disorder diagnostic service.

The list of potential participants was considered by the diagnostic team at their monthly meeting, to allow discussion of issues such as, current mental health or potentiality for distress to be caused by participation.

A letter was sent to the registered General Practitioner (GP) for all potential participants identified, describing the research and requesting permission to contact the individual (see Appendix 6.4). The GP was

asked to indicate whether they believed it was appropriate for the individual to be contacted by returning the opt-in slip in the stamped addressed envelope provided. Accurate completion of this slip was taken as evidence of the GP giving their permission for the author to make contact with the potential participant. A letter of introduction to the study was sent to all those individuals for whom permission had been received (see Appendix 6.5). This letter provided contact details for the author[20] to allow potential participants to request further information about the study.

b) Autism Spectrum Disorder specific support agency.

The recruitment process with this agency was carried out in agreement with the manager of the service. The recruitment process was based on the services established procedure for research recruitment. Initially, the author volunteered at the agency for five drop-in sessions, this was to make the author more familiar to those that access the voluntary agency. Individuals with Asperger's Syndrome or High Functioning Autism can find meeting new people anxiety provoking. Therefore, the support agency feels that to reduce any potential distress caused by participation it is important that researchers are familiar and accessible. The author was then invited to give a short presentation at a monthly group organised for individuals who have been diagnosed in adulthood. Additionally, another short presentation was arranged for an evening drop-in session. This presentation was announced in the monthly newsletter so that all individuals who were interested in finding out about the research could attend.

[20] Email, telephone, tear-off strip and stamped addressed envelope.

At this stage the Q-set statements were under review by the ethics committee. The author had been given permission by the committee to carry out the presentations and introduce the research topic but was not allowed to recruit until the statements had been approved. As such a brief reminder sheet describing the research which included contact details for the author was given to the manager of the support agency, who then distributed the sheet to those who had expressed interest.

c) Autism Spectrum Disorder specific support group.

The final recruitment route was through a support group organised and run by adults with Asperger's Syndrome. The manager of the support agency (discussed above) initially discussed the research with the group organiser who gave permission for the author to make contact and provide written information about the study. The group discussed the research in their monthly meeting and subsequently the organiser contacted the author and invited her to attend a future meeting and give a short presentation on the research.

For all recruitment routes the subsequent steps in the recruitment process were the same. The author provided the potential participants with both verbal and written information regarding the study, this was arranged at a time and place that was convenient for the potential participant (see Appendix 6.6). For all but one of the participants this information was provided face-to-face, for one participant it was not possible to arrange a first meeting and the information was provided by telephone. The potential participants were then given a minimum of 48 hours to consider the

information and decide whether to participate. After this time the author made contact with the individuals. If they chose to participate then a convenient time and location was arranged with the participant to complete the Q-sort and the demographic questionnaire.

Prior to completing the study written informed consent was gained from the participant (see Appendix 6.6 for a copy of the consent form). A number of measures were taken to ensure that participants had sufficient understandable information to allow them to make an informed decision. Communication difficulties associated with the diagnosis of Asperger's Syndrome and High Functioning Autism make it essential that all written and verbal communications are clear and unambiguous. Therefore all patient information sheets were clearly written and reviewed by the co-researcher with Asperger's Syndrome. Additionally to ensure the potential participants had fully comprehended what participation would involve, they were asked to describe the key components of the research.

Furthermore at this point participants were asked whether they would be happy to be contacted after the data analysis to receive feedback and make comments on the factors extracted. Additional consent was gained for this.

6.2.4.2 Q-sorting

For all participants, the Q-sorting and demographic interview were completed together in the same session. On average the entire session took approximately 1 to 1.5 hours, with the Q-sorting process taking approximately 45 to 60 minutes and the demographic questionnaire 15 minutes. For those recruited through the support agency or support group

the session was completed on the agencies premises, where the individual was comfortable and familiar. For those recruited through the locality diagnostic service all the sessions were completed in NHS or University property. If the location was unfamiliar to the participant then they were shown where all the exits, toilets and facilities were.

Once written consent had been gained a verbal summary of the session was provided, outlining the tasks to be completed. The participants were then provided with the conditions for instruction and directed to read them and to follow the steps outlined within. The author ensured that the instructions had been fully understood and supported the participant to start the sorting process. The instructions were kept visible throughout the process. It was highlighted to the participant that there was no right or wrong answer, and that the statements did not represent facts but were points of view or opinions. The stages that each participant followed are outlined below;

- Participants were asked to start by reading through all of the 52 statements and then splitting them into three piles;
    - *Pile one* is for statements you agree with (AGREE).
    - *Pile two* is for statements you disagree with (DISAGREE).
    - *Pile three* is for statements you neither agree nor disagree with, or that are not relevant or applicable to you (NEUTRAL).
- The author recorded the number of statements that the participant had placed in each pile on the record sheet.
- The participant was then presented with the Q-sort grid, and the continuum scale was explained.

- The participant was asked to choose from the statements in the agree pile the two statements that they most agreed with and to place them under the +5.
- The participant was then asked to do the same with the statements in the disagree pile, placing the two statements they most disagreed with under the -5.
- They were then asked to return to the agree pile and choose the next three statements they most agreed with to go underneath the + 4.

The participants were asked to keep alternating between the agree and disagree piles until they had finished them, then they were asked to move onto the neutral statements. When the participants had completed the sort they were given the opportunity to review it and to move any statements they felt they had misplaced.

When the participant was satisfied with their Q-sort, the Q-sorting grid with the statements attached was removed. The participant was then asked whether they would be happy to continue with the demographic questionnaire, the questionnaire was administered as a semi-structured interview. When this was completed there was the opportunity for questions, debrief and thanks.

6.3 Q-factor analysis

The completed Q-sorts were recorded using the Q-sort recording form. The results of each 'Q-sort' were coded numerically and these codes became the data used in the analysis (Stainton Rogers, 1991). This was done by entering the statement number into the space on the record form that corresponded to

the position of the statement on the actual Q-sort grid. The numerical data representation of each Q-sort was then entered into the statistical package, PQMethod 2.11 (Schmolk, 2002), and the analysis was carried out. All the data collected from the demographic interview was entered into an excel database, and was used along with the comments made by the participants during the sorting process for interpretation of the emergent factors.

6.4 Summary

Both phases of the methodology have been discussed. The specifics of the analysis will be considered further with the results in Chapter 7.

RESULTS SECTION.

In Chapter 7 the specifics of the participant sample is described, along with the Q-factor analysis and subsequent factor interpretation.

CHAPTER 7: RESULTS

7.1 Summary of overall participant sample

Eighteen individuals participated in the study completing both the Q-sort and the semi-structured interview. All participants successfully completed both these tasks within a single session.

7.1.1 Recruitment

There were three routes (diagnostic service, support agency, support group) utilised for recruitment as outlined in Chapter 6. Having the different routes allowed for a range of individuals to be recruited whose circumstances and access to services differed. Although individuals were not asked whether they were currently engaging with mental health services, anecdotally it appeared those recruited via the diagnostic service were less likely to be accessing any other external support. The recruitment numbers are summarised in Table 7.1 and the recruitment processes for each route covered below.

Table 7.1: The number of participants recruited from each of the different routes

	Route 1: diagnostic service	***Route 2: support agency***	***Route 3: support group***	***Total***
No. of participants recruited	6	7	5	18

- **Route 1**: A total of fifty individuals were identified through the diagnostic service as potential participants. Letters were sent outlining the study to the GPs responsible for these individuals care. Thirty-eight responses were received from the GPs, twenty-one

agreed for their patients to be contacted. Letters were sent out to potential participants, 10 individuals responded either by mail, email or telephone. Six individuals participated, and a further four individuals were interested however it was not possible to meet with them within the time frame.

- **Route 2**: Two research presentations were held at the support agency allowing individuals who were interested to come and find out more about the study. This process resulted in seven participants being recruited.
- **Route 3**: The author was invited to give a research presentation to a support group run by adults with Asperger's Syndrome. Individuals were provided with contact details for the author should they wish to participate. Five individuals were recruited.

7.1.2 Demographic information

7.1.2.1 Gender and age

The majority of participants were male, with two female and sixteen male. The greater number of males is consistent with the higher prevalence of Autism Spectrum Disorders in males than females. The mean age at participation was 44.5 years (SD = 12.6).

7.1.2.2 Diagnosis

Seventeen individuals had received their diagnosis through the NHS, while one had sought a private referral for diagnosis. Seventeen had received a diagnosis of Asperger's Syndrome, with only one individual being diagnosed with High Functioning Autism. Due to the limited number

diagnosed with High Functioning Autism no differentiation will be made when interpreting findings. Table 7.2 provides a summary.

Table 7.2: Summary of the diagnosis source and type of diagnosis

	Diagnosis source		***Type of diagnosis***	
	NHS	Private	Asperger's Syndrome	High Functioning Autism
Number of participants	17	1	17	1

The mean age at diagnosis was 39.4 years (SD = 12.8), with a range of 44 years spanning from 18 years up to 62 years. The mean length of time since diagnosis was 25.5 months (SD = 21.1), with a range of 79 months from 8 months to 87 months. Table 7.3 provides a summary.

Table 7.3: Summary of the age at diagnosis and length of time since diagnosis for participants

	Mean (SD)	***Range***	***Minimum***	***Maximum***
Age at diagnosis (years)	39.4 (12.8)	44	18	62
Length of time since diagnosis (months)	25.5 (21.1)	79	8	87

7.1.2.3 Education and employment

Seven participants had completed a university degree, with three going onto complete post-graduate qualifications. A further three were currently completing their undergraduate degree. Two individuals had attended college and gained diplomas, while two had left school with highers and one with standard grades. Seven of the participants were in employment, two were full time students, two retired and a further seven were currently unemployed.

7.2 Q-factor Analysis

The Q-data analysis package PQmethod 2.11[21] (Schmolk, 2002) was used to analyse the data. The package requires the statement set (abbreviated to 60 characters) to be entered, and information to be provided on the format of the Q-sort grid. The eighteen completed Q-sorts were entered and analysed using principal components analysis. Initially correlation matrices were produced to allow consideration of the relationships between individual Q-sorts.

7.2.1 Factor extraction

Principal components analysis as run by PQmethod 2.11 automatically extracts eight factors. Five of these factors had eigenvalues of greater than 1.00 (see Table 7.4). Eigenvalues are a measure of the relative contribution of a factor to the explanation of the total variance in the correlation matrix. When the value is greater than one the factor is considered to explain more variance than one single Q-sort alone. The aim is to select factors which allow for the clearest elucidation of the shared understandings of some adults with Asperger's Syndrome or High Functioning Autism while differentiating them from others.

The fifth factor only just reached this level of significance and had only one Q-sort significantly loading. Therefore, following statistical consideration this factor was discarded due to concerns that any conclusions or interpretations drawn from it would be too idiosyncratic and unreliable. It was therefore possible to reduce sixteen of the original set of eighteen Q-sorts

[21] PQmethod 2.11 (Schmolk, 2002) is available for free download at http://www.lrz-muenchen.de/~schmolck/qmethod/ and is compatible with windows.

to four independent factors which explained 64 percent of the variance. These four factors were taken forward for further analysis.

Table 7.4: Factor results from PCA analysis of the Q-sort data.

Factors[22]	*Eigenvalue*	*Percentage variance explained*	*Cumulative percentages*
1*	5.8935	33	33
2*	2.6430	15	47
3*	1.7627	10	57
4*	1.2457	7	64
5	1.0001	6	70
6	0.8765	5	75
7	0.7276	4	79
8	0.6444	4	82

7.2.2 Factor rotation

The four factors were rotated to a simple structure using the varimax procedure. Varimax rotation clarifies the structure of the selected factors by maximising the amount of variance explained by the extracted factors (Watts & Stenner, 2005). Factor loadings for factor exemplars are reported in Table 7.5 with the entire rotated factor matrix included in Appendix 7.2

Only those Q-sorts which loaded significantly and cleanly onto one factor were selected as exemplars for that factor (McKeown & Thomas, 1988). Factor exemplars share a similar pattern of sorting of the statements, and therefore those that load significantly onto the same factor can be assumed to share a distinct understanding. In this study significance for selecting factor exemplars[23] was taken as being 0.45, which is considered to be a rigorous

[22] Factors marked with a * are those with an eigenvalue >1.00 and that were selected for varimax rotation.

[23] Additionally the statistical package PQMethod 2.11 automatically identifies factor exemplars in a process called pre-flagging, before allowing you to manually adjust them. According to the PQMethod (Schmolck, 2002) the ***pre-flagging algorithm*** is designed to flag 'pure' cases only, according to the rule: Flag loading ***a***

level in Q-methodological studies (Stephenson, 1953) and accepted in principal components analysis in general (Tabachnick & Fidell, 2007). This level has been used in previously published studies (e.g. Day *et al*., 1996; Jones *et al*., 2003).

Table 7.5: Rotated factor matrix

Participants	*Factor 1*	*Factor 2*	*Factor 3*	*Factor 4*
P1	0.63*			0.46
P2	0.54*	0.44		
P3	0.78*			
P4				0.74*
P5	0.50	0.52		
P6		0.63*		
P7	0.83*			
P8				0.61*
P9			0.75*	
P10	0.76*			
P11			0.83*	
P12	0.71*			
P13		0.70*		
P14	0.42		0.47	
P15		0.45*		
P16	0.64*			
P17		0.78*		
P18		0.86*		

Note. Loadings correct to two significant figures
* Participants loading significantly (>0.45) on only one factor used as factor exemplar for next stage of analysis

As Table 7.5 shows there were four Q-sorts where there was potential for confusion due to confounding sorts loading on more than one factor. Participants 5 and 14 both failed to load cleanly onto one factor. It is important to avoid using participants as exemplars if they do not load cleanly onto one factor (Donner, 2001). As such both participants were excluded from the next stage of the analysis, but the sorts were considered again during the interpretative stage of the analysis.

***if* (1)** $a^2 > h^2/2$ (factor 'explains' more than half of the common variance)
***and* (2)** $a > 1.96 / SQRT(nitems)$ (loading 'significant at p<.05').

Participants 1 and 2 could also be considered as confounded sorts. Participant 1 loaded significantly onto factor 1 (0.63) but it also just reached significance on factor 4 (0.46). Due to the considerable difference between the two loadings and as it only just reached significance on factor 4 it was decided to keep this Q-sort as an exemplar for factor 1[24]. Participant 2 loaded significantly only onto factor 1 (0.54) but had a high loading on factor 2 (0.44). Further analysis was completed both with and without this participant as an exemplar and comparisons of the outcome made. It was concluded that inclusion of this participant made no substantial changes at the interpretation stage.

For a factor to be seen as interpretable it must have at least two Q-sorts that load significantly on it alone[25]. All of the four factors had at least two Q-sorts loading significantly on them with factor 1 having seven Q-sorts, factor 2 having five Q-sorts, factor 3 having two Q-sorts and factor 4 having two Q-sorts (see Table 7.6). For both factor 3 and 4 there were only two Q-sorts loading significantly, these factors must therefore be considered tentatively. The interpretations and understandings drawn from these factors are likely to be less coherent and more difficult to outline. Any generalisations made from these two factors must be done cautiously as it is likely that if further participants were recruited the stability of these factors would be affected. However, the author believed they were important to include to facilitate discussion and the formation of further questions. Therefore the decision was

[24] Participant 1 was identified as an exemplar by PQMethod 2.11, this was also supported by the advice in advisory Q-methodology texts on manual flagging (e.g. Donner, 2001).

[25] When a five-factor solution was considered both the fourth and fifth factors only had one Q-sort significantly load upon them, this was further evidence for the discarding of the fifth factor.

made to maintain a four factor structure and conduct further analysis to identify the extent to which each exemplar contributed to that factor.

Table 7.6: Total number of significant Q-sorts loading on each factor

	Factor 1	*Factor 2*	*Factor 3*	*Factor 4*
Total number of sig. Q-sorts	7	5	2	2

7.2.3 Factor definition

As outlined in Chapter 3 after the selection of exemplar Q-sorts for each factor further analysis is carried out to produce a best-estimate Q-sort for each factor. To do this, the individual loadings of each exemplifying Q-sort onto a factor are considered (see Table 7.5), to establish the overall contribution they should make to the best-estimate (Watts & Stenner, 2005). Based upon the established contribution, each individual statement within the exemplifying Q-sort is proportionally weighted. This allows all exemplifying Q-sorts for a factor to be combined and a best-estimate produced. The statistical package PQMethod 2.11 conducts this process. The best-estimate Q-sorts for each factor are represented in the factor array along with the mean and standard deviation of all the statements for each factor (Table 7.7).

Analysis of the factor array (see Table 7.7) along with the normalised factor scores and the distinguishing statements for each factor is the first step in interpreting the factors. The normalised factor scores list z-scores for each factor and are listed in rank order, giving an additional representation of the best-estimate Q-sort for the factor (Donner, 2001). As discussed in Chapter 3, the distinguishing statements are those that have been ranked significantly differently between factors. The normalised factor scores are shown in

Appendix 7.3 and the distinguishing statements have been highlighted in bold in the factor array (Table 7.7). Both will be discussed below with the factor interpretations.

Table 7.7: Factor arrays for factors 1-4

Q-item	*Factor 1 (n=7)*			*Factor 2 (n=5)*			*Factor 3 (n=2)*			*Factor 4 (n=2)*		
	L[26]	**M**[27]	**SD**[28]	**L**	**M**	**SD**	***L***	**M**	**SD**	**L**	***M***	**SD**
1.	1	1.57	1.62	0	0.60	3.13	**5***	4.00	0.00	1	0.50	2.12
2.	1	0.43	1.27	-2	-0.60	2.30	2	1.00	1.41	-2	-2.50	3.54
3.	0	0.43	1.99	**-4***	-2.20	1.79	**3***	3.50	2.12	0	-0.50	2.12
4.	0	-0.14	2.12	-3	-2.40	1.95	-3	-3.00	1.41	-1	-1.00	1.41
5.	4	2.43	1.27	2	1.60	0.55	4	3.50	2.12	1	0.00	0.00
6.	**3***	2.14	2.48	1	0.40	0.89	**5***	4.00	1.41	-1	-1.00	1.41
7.	**2***	1.57	1.72	-4	-2.60	1.82	-3	-3.00	0.00	-2	-1.50	0.71
8.	**4***	2.43	2.23	-1	-0.60	1.52	1	0.50	3.54	0	-0.50	0.71
9.	-1	-0.57	1.51	-2	-0.80	3.42	-3	-2.50	0.71	1	0.50	0.71
10.	0	0.86	1.35	2	2.00	1.87	2	1.50	0.71	0	-0.50	2.12
11.	**5***	2.29	2.06	1	-0.40	1.82	1	0.50	0.71	-1	-0.50	2.12
12.	0	0.71	1.38	1	0.00	1.22	0	0.00	1.41	**3***	3.00	1.41
13.	2	1.71	1.60	2	1.60	1.52	1	1.00	0.00	**4***	3.50	0.71
14.	4	2.00	2.31	0	-0.20	1.10	1	1.00	1.41	2	2.00	0.00
15.	1	1.29	2.36	1	0.40	0.55	-1	-0.50	0.71	**4***	3.00	1.41
16.	1	1.00	2.31	-1	-0.80	0.84	-1	-0.50	0.71	2	3.00	2.83
17.	**3***	1.43	1.99	0	0.60	1.14	-1	-1.00	1.41	0	0.00	1.41

[26] Factor array – location of statement in best-estimate Q-sort for each factor.
[27] Mean ranking of each statement for each factor
[28] Standard deviation of each statement for each factor

18.	**2***	1.57	1.99	-1	-0.80	2.39	-2	-1.50	2.12	0	0.50	4.95
19.	**1***	1.14	1.77	-2	-0.80	2.39	-1	-1.00	0.00	**5***	4.00	1.41
20.	3	2.14	1.95	2	1.60	1.82	-1	-1.00	4.24	-2	-1.50	2.12
21.	5	2.57	1.51	2	1.80	1.30	1	0.50	2.12	1	1.00	1.41
22.	**1***	0.86	2.41	-5	-3.00	1.41	-5	-5.00	0.00	-4	-3.50	2.12
23.	**2***	1.57	2.44	-2	-1.00	1.22	-2	-1.00	2.83	-1	-0.50	2.12
24.	-1	0.29	1.50	-1	-0.20	1.48	0	0.50	3.54	**5***	4.00	1.41
25.	3	2.00	1.53	0	-0.20	1.10	2	1.50	2.12	2	2.00	2.83
26.	1	1.57	2.82	4	3.00	1.87	3	2.50	0.71	**-2***	-1.00	2.83
27.	**-5***	-4.00	1.15	-3	-3.00	1.58	**3***	2.50	2.12	-3	-2.50	2.12
28.	-3	-2.86	1.33	-4	-3.40	1.52	**2***	1.00	0.00	**-1***	-1.50	2.12
29.	-4	-3.29	0.95	-3	-2.40	0.55	-2	-1.50	0.71	-4	-3.00	0.00
30.	**-2***	-2.43	1.27	2	2.20	2.77	1	1.00	1.41	0	-1.00	2.83
31.	**-4***	-3.14	1.21	**-2***	-1.20	2.49	**3***	3.50	2.12	**1***	0.50	2.12
32.	-2	-0.71	1.38	-1	-0.60	1.14	**4***	3.50	0.71	**-4***	-2.00	2.83
33.	0	0.14	1.57	3	2.80	1.30	-1	-0.50	0.71	3	2.50	0.71
34.	-1	0.86	3.48	**4***	2.20	3.70	2	1.50	3.54	2	1.00	2.83
35.	-2	-2.71	1.60	-3	-2.00	2.83	-2	-1.50	0.71	**-5***	-4.50	0.71
36.	-1	-0.71	1.98	-2	-1.40	2.30	0	0.50	2.12	-3	-2.00	0.00
37.	-2	-1.86	0.90	0	0.00	2.74	0	0.50	0.71	-1	-1.00	0.00
38.	-1	-0.57	0.79	-1	-0.80	1.79	0	0.00	2.83	**-5***	-3.00	2.83
39.	0	0.43	1.40	1	0.40	1.52	2	1.50	2.12	1	0.50	2.12
40.	-3	-2.43	1.27	**1***	0.60	2.61	-3	-3.00	1.41	-2	-1.50	0.71
41.	-2	-1.29	1.89	3	1.00	3.00	-1	-1.00	1.41	2	2.00	0.00
42.	-3	-2.71	1.38	**0***	-1.00	2.55	-4	-3.50	0.71	**3***	2.00	4.24

43.	-4	-3.43	1.51	**3***	2.00	0.71	-4	-3.50	0.71	-2	-2.00	2.83
44.	-2	-1.71	2.50	0	-0.60	1.95	**-5***	-4.50	0.71	0	-1.00	2.83
45.	**-3***	-2.43	2.23	**5***	3.60	1.34	0	0.00	1.41	-1	-0.50	2.12
46.	2	1.71	1.80	5	3.80	1.30	1	1.00	0.00	3	3.00	0.00
47.	0	0.43	2.07	**3***	2.40	2.61	-2	-1.50	2.12	-3	-1.50	3.54
48.	-1	-0.43	1.51	0	-0.40	1.95	-2	-2.00	0.00	1	1.00	0.00
49.	0	0.43	1.40	1	0.80	2.05	-1	-0.50	0.71	**-4***	-2.00	2.83
50.	2	1.14	1.95	-1	-0.40	1.82	0	0.50	0.71	**4***	3.50	0.71
51.	**-1***	-0.14	1.68	4	2.60	1.52	4	3.50	0.71	**2***	1.00	1.41
52.	-5	-3.57	1.27	-5	-4.20	1.30	-4	-3.00	2.83	**0***	-0.50	0.71

7.3 Factor interpretation

Interpretations of the factors were guided by the information gathered through the semi-structured interviews with the participants, qualitative comments made while they were completing the Q-sort, and the current understanding within the literature. Comparisons were made across the different factor arrays and qualitative analysis of the best-estimate Q-sorts for each factor was conducted, particularly focussing on statements identified as distinguishing between the factors[29]. It would be helpful to validate the researcher's interpretations with the participants', however it has not been possible to do this within the time frame of this study. An outline of each of the four factors is given below and illustrative best-estimate Q-sorts for each factor are included in Appendix 7.4.

[29] In the following section statements are used as illustrations, all the statements presented are those identified as distinguishing statements during the analysis. Therefore, where used as an illustration their ranking is significantly different to their ranking in other factors ($p<0.05$). The ranking is the ranking of the best estimate Q-sort.

7.3.1 FACTOR 1: 'An important part of me'

7.3.1.1 Factor summary

As outlined in Table 7.5, seven Q-sorts loaded cleanly and significantly onto this factor making it the principal component, accounting for 33 percent of the variance within the entire participant group. One confounded Q-sort (P5) also loaded significantly onto this factor.

Table 7.8 shows the details of those participants exemplifying Factor 1. Of importance in this group is that all but one of the participants stated themselves to be self-motivated in pursuing diagnosis, with the majority being clear that they were happy with their diagnosis. Five of the seven had achieved degree level education and only one was not either in employment, retired or a full-time student. The age at which diagnosis was received ranged from 19 to 55 years, and the length of time since diagnosis from 10 to 25 months. All but one of the participants were male.

Table 7.8: Summary information for 7 participants who exemplify factor 1.

	Age at diagnosis[30] (years)	***Time since diagnosis (months)***	***Motivation for diagnosis***	***Happy with diagnosis?***	***Loading***
P1	45-55	25	Self	yes	0.63
P2	45-55	13	Self	Not sure	0.54
P3	18-25	14	Self	yes	0.78
P7	45-55	14	Self	yes	0.83
P10	45-55	20	Self	yes	0.76
P12	35-45	10	Other	yes	0.71
P16	25-35	23	Self	yes	0.64

7.3.1.2 Description of the factor

All the participants loading significantly onto Factor 1 indicated their acceptance of their diagnosis by disagreeing with the statement that states

[30] Age ranges were used to protect anonymity.

the contrary (52. I do not accept my diagnosis of AS/HFA). One participant commented that they accepted their diagnosis as it has been a very good model for understanding themselves, fitting with how they think and with their experiences. This factor was the only factor to show strong agreement with the following statement:

11. *I would not be me if the AS/HFA was not there (+5)*

One person explained the diagnosis was now tied into their identity while another felt the diagnosis had allowed them to develop a better identity for themselves. At the same time participants strongly dismissed any reason for shame or embarrassment at their diagnosis:

27. *I am ashamed of having a diagnosis of AS/HFA (-5)*

One person felt that they could not be ashamed of something that had helped them, while another felt they had done nothing wrong to be ashamed of. Interestingly, the majority of participants loading on this factor had self-motivated their diagnosis describing having found information out themselves about it through the internet, reading or on television, and connected with it and sought out a diagnosis only as clarification.

Participants showed agreement with statements that reflect positive consequences of having a diagnosis:

8. *Having a diagnosis of AS/HFA allows me to move on from difficulties in the past (+4)*

6. *Having a diagnosis of AS/HFA gives me answers to my previous difficulties (+3)*

7. *Having a diagnosis of AS/HFA gives me control over my life (+2)*

Two participants indicated that greater understanding and insight helped them to move on. Participants loading significantly on this factor disagreed to a greater extent than the other factors with the following statements;

31. *Having a diagnosis of AS/HFA makes me feel confused about myself (-4)*

30. *It is traumatic having AS/HFA (-2)*

51. *AS/HFA is a hard condition to live with (-1)*

All but one of the participants indicated they were happy with the diagnosis, and the participant who suggested they were unsure explained that it was a relief. One participant explained that they felt their life had come together more since receiving the diagnosis and another said it had been an 'ah ha' moment providing lots of answers.

Participants who's Q-sorts loaded significantly onto this factor indicated that they felt Asperger's Syndrome and High Functioning Autism could be advantageous for some types of work, particularly in systems-oriented fields such as sciences, engineering and IT. This understanding was further supported by agreement with the following statements:

18. *Having AS/HFA allows me to come up with ideas that nobody else can (+2)*

22. *Having AS/HFA is a gift (+1)*

All of the individuals were academic high achievers, with five of the seven having university degrees and two of these having gone on to complete postgraduate study. The majority had studied subjects where a systems-oriented view would be an advantage. Only one individual loading significantly on this factor was unemployed.

Participants who loaded onto this factor showed stronger disagreement, compared with those loading onto other factors, with the traditional medical

view that Asperger's Syndrome or High Functioning Autism is an impairment, psychiatric condition or disability:

45. *AS/HFA is a lifelong disability (-3)*

Two participants explained that having Asperger's Syndrome had not prevented them achieving in life, therefore how could it be seen as an impairment or disability? Instead participants supported the more recently developed autistic spectrum understanding where difference is the key concept:

17. *The differences that I have because of AS/HFA are on underlying dimensions on which all people vary (+3)*

23. *Having a diagnosis of AS/HFA does not mean I am part of a group of people who are ill (+2)*

One participant commented that differences are often common behaviours expressed in a more extreme form and that all individuals have autistic traits, while another commented that just because you present as not being the norm others can wrongly assume that you are ill or have a condition.

The best-estimate Q-sort for Factor 1 is outlined in Appendix 7.3 with the distinguishing statements highlighted (*).

7.3.1.3 Factor review

This factor appears to be characterised by a view of Asperger's Syndrome and High Functioning Autism which acknowledges positive consequences of receiving a diagnosis and identifies with the advantages it can provide people with in certain lines of work. There is a dismissing of a disability explanation and a support of explanations based upon difference. It appears that individuals loading significantly onto this factor had anticipated their

diagnosis and has been able to successfully integrate their diagnosis with their identity, allowing them to move forward in their lives.

7.3.2 FACTOR 2: 'It is a lifelong disability'

7.3.2.1 Factor summary

Factor 2 is the second largest factor with five participants loading cleanly and significantly onto it, as such it accounts for 15 percent of the variance within the entire participant group. One confounded Q-sort (P5) also loaded significantly onto factor 2.

Table 7.9 shows the details of those participants exemplifying Factor 2. Within this factor there were three individuals who were self-motivated to pursue the diagnosis and a further two for whom the process was driven by others. Two of the individuals felt they were unsure whether they were happy with their diagnosis. Similar to Factor 1, all had achieved highly academically with three out of the five having academic degrees, and only two currently in employment. The age at which diagnosis was received ranged from 18 to 51 years and the length of time since diagnosis from 8 to 87 months. All participants were male.

Table 7.9: Summary information for 5 participants who exemplify Factor 2.

	Age at diagnosis[31] (years)	***Time since diagnosis (months)***	***Motivation for diagnosis***	***Happy with diagnosis?***	***Loading***
P6	35-45	11	Self	Yes	0.63
P13	18-25	26	Self	Not sure	0.70
P15	45-55	8	Other	Yes	0.45
P17	18-25	72	Self	Yes	0.78
P18	45-55	87	Other	Not sure	0.86

[31] Age ranges were used to protect anonymity.

7.3.2.2 Description of the factor

Similar to Factor 1 the participants loading significantly on this factor showed their acceptance of their diagnosis by their disagreement with the statement that states the contrary (52. I do not accept my diagnosis of AS/HFA). Three of the five individuals felt they were happy with their diagnosis, while two remained unsure. Similar to Factor 1 there was a degree of anticipation by some of the participants who were simply looking for clarification. However, two individuals indicated that they had to force themselves to accept the diagnosis.

Similar to Factor 1 there was no sense that the individuals were struggling to understand themselves:

31. *Having a diagnosis of AS/HFA makes me feel confused about myself (-2).*

However, the view of Asperger's Syndrome and High Functioning Autism that those loading onto Factor 2 held differed from the other factors. Factor 2 is the only factor to support a disability view of Asperger's Syndrome and High Functioning Autism:

45. *AS/HFA is a lifelong disability (+5)*

43. *AS/HFA is an impairment (+3)*

Two participants indicated that they agreed strongly with these statements as they felt they were hard facts that Asperger's Syndrome and High Functioning Autism are lifelong disabilities.

The 'lifelong' nature of the diagnosis was emphasised by this factor:

47. *There is nothing I can do to change me having AS/HFA (+3)*

Two participants commented that it would always be part of them. One participant stated that this realisation caused him to experience a period of

depression, summarising his diagnosis as a prison sentence with no sign of parole. This understanding is congruent with the participants strongly disagreeing with the following statement:

3. *Having a diagnosis of AS/HFA is like a new beginning to my life (-4)*

Within this factor there is no clear acknowledgement of the positive consequences of receiving a diagnosis or of potential advantages associated with having Asperger's Syndrome. This is highlighted by three participants referring to it as a curse or a bad gift in response to the statement suggesting it may be a gift.

Participants loading onto Factor 2 agree strongly with Asperger's Syndrome and High Functioning Autism being complicated conditions which affect many aspects of a person's day to day life, including being sociable and coping with daily tasks of living. This is highlighted by agreement with the following statements:

34. *I feel disconnected from other people, because I have AS/HFA (+4)*

40. *Because I have AS/HFA I have an extensive need for support from my family and society (+1).*

Two individuals indicated that feeling disconnected from others is tied up with difficulty understanding emotions and how others are feeling, while one indicated the need for support to cope with outside world and build relationships. There was relative neutrality about succeeding and achieving:

42. *Having AS/HFA means that I will never achieve as well as my peers (0)*

Two individuals although highly educated were at the time of participation unemployed. Interestingly, four of the individuals reported seeking support for mental health difficulties at the time of their diagnosis.

The best-estimate Q-sort for Factor 2 is outlined in Appendix 7.3 with the distinguishing statements highlighted (*).

7.3.2.3 Factor review

Like Factor 1, individuals loading significantly on this factor appear to have accepted their diagnosis, however, whether this is due to a necessity to accept it is unclear. They advocate an understanding of Asperger's Syndrome and High Functioning Autism based upon a disability model, with particular emphasis on it being lifelong. Alongside this there is a particular acknowledgement of its complicated nature and associated difficulties, in particular in relating to others and the impact this has on support requirements and achievement.

7.3.3 Factor 3: 'Confused about myself'

7.3.3.1 Factor summary

Only two participants loaded cleanly and significantly onto Factor 3, explaining 10 percent of the variance within the entire participant sample. One confounded Q-sort (P14) also loaded significantly on this factor. As discussed earlier due to there only being two factor exemplars any interpretations drawn about Factor 3 have been made tentatively and the limitations in terms of generalisability and coherence must be acknowledged.

Table 7.10 shows the details of those participants exemplifying Factor 3. Both of the two participants indicated that motivation for their diagnosis had been driven by others, and that they had not considered Asperger's Syndrome or High Functioning Autism as explanations for difficulties previously. One indicated happiness with the diagnosis and the other was unhappy. Neither

was receiving support from families. Both of the participants were currently unemployed although one had academically achieved well, gaining an academic degree. One participant was male and the other female.

Table 7.10: Summary information for two participants who exemplify factor 3.

	Age at diagnosis (years)	***Time since diagnosis (months)***	***Motivation for diagnosis***	***Happy with diagnosis?***	***Loading***
P9	35-45	17	Other	no	0.75
P11	18-25	24	Other	yes	0.83

7.3.3.2 Description of the factor

Participants loading onto Factor 3, like the previous two factors, showed an acceptance of their diagnosis by their disagreement with the statement stating the contrary (52. I do not accept my diagnosis of AS/HFA). However, both factor exemplars indicated conflict about this acceptance, expressing agreement yet feeling reluctance and experiencing difficulty coming to terms with it. Interestingly, neither had considered Asperger's Syndrome or High Functioning Autism as an explanation for their difficulties prior to receiving the diagnosis.

Unlike the other factors participants reported greater confusion and less control as a result of the diagnosis:

31. *Having a diagnosis of AS/HFA makes me feel confused about myself (+3)*

One participant explained the diagnosis had initially provided them with explanations but had subsequently left them worrying about what to do next.

Factor 3 is distinguished from the other factors by high ranking of statements acknowledging the positive results of receiving a diagnosis:

6. *Having a diagnosis of AS/HFA gives me answers to my previous difficulties (+5)*

1. *Having a diagnosis of AS/HFA is a relief (+5)*

3. *Having a diagnosis of AS/HFA is like a new beginning to my life (+3)*

All individuals described how they had always felt their was something wrong or different about them until they had received the diagnosis, and how this had linked in with their previous experience of mental health difficulties. However, finding out allowed them to understand and accept themselves and to start a new chapter to their lives.

At the same time as agreeing with the statements above they agreed strongly with the following statements:

32. *Having a diagnosis of AS/HFA means that I am labelled, stereotyped and placed in a group (+4)*

27. *I am ashamed of having a diagnosis of AS/HFA (+3)*

28. *Having a diagnosis of AS/HFA makes me angry (+2)*

Both factor exemplars described shame at having been diagnosed, with one participant commenting that they knew they should not be ashamed. Both explained they were reluctant to share their diagnosis with others, including family as they felt it may be misunderstood. One participant referred to seeing Asperger's Syndrome and High Functioning Autism as a curse.

Participants loading significantly onto this factor dismissed the understanding of Asperger's Syndrome or High Functioning Autism as being an impairment or illness, with individuals strongly disagreeing with the following statement:

44. *AS/HFA is a psychiatric condition (-5)*

However, there is neutrality about alternative models for understanding the diagnosis i.e. a spectrum or difference. This may be as a result of participants not having knowledge about alternative understandings, as was indicated by their comments about a number of statements.

The best-estimate Q-sort for Factor 3 is outlined in Appendix 7.3 with the distinguishing statements highlighted (*).

7.3.3.3 Factor review

Individuals loading on Factor 3 appeared to have accepted their diagnosis but it seemed to have been a reluctant acceptance. They describe benefits of diagnosis, such as gaining answers and explanations, yet expressed shame at being diagnosed. They dismissed a psychiatric or illness understanding of Asperger's Syndrome and High Functioning Autism but did not have a clear alternative model. Individuals seemed to have been left feeling confused about themselves following diagnosis.

7.3.4 FACTOR 4: 'Support can bring improvement'

7.3.4.1 Factor Summary

Two participants exemplify Factor 4, explaining 7% of the variance for the entire participant group. As with Factor 3 due to there only being two factor exemplars any interpretations drawn about Factor 4 have been made tentatively and the limitations in terms of generalisability and coherence must be acknowledged.

Table 7.11 shows the details of those exemplifying Factor 4. One individual was self motivated to seek a diagnosis while for the other the motivation was

professional. Similar to the rest of the participants they were academic high achievers, with one individual being unemployed. Both participants were male.

Table 7.11: Summary information for two participants who exemplify factor 4.

	Age at diagnosis (years)	*Time since diagnosis (months)*	*Motivation for diagnosis*	*Happy with diagnosis?*	*Loading*
P4	35-45	24	Other	Yes	0.75
P8	55-65	35	Self	DK	0.61

7.3.4.2 Description of the factor

Factor 4 was the only factor not to show strong agreement with the diagnosis, showing a neutral response to the statement:

52. *I do not accept my diagnosis of AS/HFA (0).*

Similar to Factor 3 there was some agreement with a sense of confusion about having Asperger's Syndrome or High Functioning Autism:

31. *Having a diagnosis of AS/HFA makes me feel confused about myself (+1)*

However, neither of the participants passed comment on their actual diagnosis.

Factor 4 is the only factor to strongly acknowledge positive practical consequences of receiving a diagnosis and to suggest that there is the possibility of change and improvement when you have Asperger's Syndrome or High Functioning Autism:

24. *Having a diagnosis of AS/HFA means that I can access supports and services (+5)*

50. *Weaknesses associated with having AS/HFA can be made better by specific types of therapy (+4)*

Unlike the other factors they showed less agreement with it being lifelong:

26. *AS/HFA will stay with me all through my life (-2)*

Interestingly both of these individuals reported accessing regular support. One individual commented that they wouldn't have managed with practical issues like jobs applications, interviews and completing forms without this support.

There was an agreement with statements that discussed negative consequences of having Asperger's Syndrome or High Functioning Autism, with particular reference to fitting in with society, feeling disconnected and making friends. There was a greater agreement with the following statement than for other factors:

42. *Having AS/HFA means that I will never achieve as well as my peers (+3)*

Both participants commented on having intellectual abilities to succeed but how difficulties associated with work e.g. fitting in, made it harder:

19. *Many difficulties people with AS/HFA face are due to society rather than the condition itself (+5)*

However, the possibility of being part of society and having a useful role was emphasised:

12. *I can belong to a community even if I have a diagnosis of AS/HFA (+3)*

35. *Society has little use for people with AS/HFA (-5)*

38. *I am judged negatively because I have AS/HFA (-5)*

One participant acknowledged that certain autistic traits, such as attention to detail and intense focus, have been essential to developments in society.

Factor 4 agrees with a model for understanding Asperger's Syndrome and High Functioning Autism which is based upon difference but acknowledges a biological basis:

15. *Having AS/HFA means that there is a difference in the construction of your brain (+4)*

13. *AS/HFA affects people in many different ways and to varying degrees (+4)*

There is disagreement with an impairment model but there is an understanding that there is variability in the type and extent of difficulty an individual has.

The best-estimate Q-sort for Factor 4 is outlined in Appendix 7.3 with the distinguishing statements highlighted (*).

7.3.4.3 Factor review

Individuals loading significantly onto factor 4 appeared to have gained benefit from the practical supports they have received as a consequence of their diagnosis. There was an acknowledgement of the difficulties associated with Asperger's Syndrome and High Functioning Autism, in particular relating to building relationships. However, it was indicated that this should not hold you back or prevent you having a role within society. A biological difference model is used for understanding Asperger's Syndrome and High Functioning Autism.

7.4 Summary

The findings from the Q-factor analysis have been outlined and the interpretations of the four factors described. The interpretations will be discussed further in chapter 8.

DISCUSSION SECTION.

The findings from the Q-factor analysis and interpretation will be discussed in Chapter 8.

CHAPTER 8: Discussion

The discussion will involve an overview of the study before considering the significant findings. Following this the author will discuss the successes and limitations of the study. Finally the clinical implications and scope for future research will be outlined.

8.1 Overview of study

This study explored how Asperger's Syndrome and High Functioning Autism were understood by individuals' who had received the diagnosis in adulthood, with particular focus on the range of beliefs and understandings held. Recent research had suggested links between beliefs held about Asperger's Syndrome and High Functioning Autism and the experience of diagnosis and post-diagnostic identity development (Cousins, 2001; Molloy & Vasil, 2004; Punshon, 2006). The recent research was vague about the specifics of the beliefs, broadly referring to three main theoretical conceptualisations i.e. disability, difference and advantage. However, a review of the current understanding of Asperger's Syndrome and High Functioning Autism within the professional community indicated there was scope for significant variability in the beliefs individuals' held. The study was exploratory and had no specific hypotheses.

Q-methodology was chosen to examine the range of beliefs individuals held and to identify common-ways in which Asperger's Syndrome and High Functioning Autism were understood. The study sampled a range of individuals from a number of different sources, across a wide age range at point of diagnosis, and across a varying length of time since diagnosis. Four distinct factors or common-ways of understanding, Asperger's Syndrome

and High Functioning Autism, were identified and could be meaningfully interpreted. These four factors were named by the author *'An important part of me'*, *'It is a lifelong disability'*, '*Confused about myself*, and '*Support can bring improvement'*.

8.2 Significant findings from the exploration of beliefs

The Q-factor analysis and subsequent interpretation highlighted three significant issues on which the factors differed. These were termed 'acceptance and adjustment', 'consequences of diagnosis' and 'theoretical conceptualisations'. All three will be outlined below with reference to each specific factor.

8.2.1 Acceptance and adjustment

Within the study all participants expressed agreement with their diagnosis, although the extent to which it was accepted and understood appeared to differ between the factors. The motivation for seeking a diagnosis, i.e. whether it was self or other motivated, appeared to be important for the extent to which the diagnosis was accepted.

All but one of the individuals who loaded significantly onto Factor 1 had self-motivated their diagnosis. Many described a process of discovering Asperger's Syndrome for themselves through television, reading or the internet; then searching for information to find out more, before seeking out an official diagnosis only as clarification. This discovery of Asperger's Syndrome and clarification is similar to that described in two of the autobiographical accounts (Birch, 2003; Mitchell, 2005), and incorporates a process of information gathering and sense-making (Cousins, 2001; Molloy &

Vasil, 2004; Punshon, 2006) which appears to be very much of the individuals own volition.

Individuals associated with Factor 1 showed the strongest acceptance of their diagnosis. It was the only factor to show strong agreement with statements that acknowledged that Asperger's Syndrome and High Functioning Autism were tied up with an individuals identity e.g. *I would not be me if the AS/HFA was not there*. These individuals were able to present a balanced representation which included the difficulties but also referred to potential advantages. It is possible that due to success within their academic and work fields, which for all would be expected to benefit from a systems-oriented mind, they were better able to reflect on potential advantages. Hans Asperger himself suggested that those who are able to find a niche within work which utilises their skills are likely to have a more positive outcome (Asperger, 1945/1991).

Those individuals loading onto Factor 2 also showed a strong acceptance of the diagnosis, but there was less agreement with it being part of their identity. There was a greater sense that individuals felt they *had* to accept their diagnosis as they had been diagnosed with it. The holistic understanding of the best-estimate Q-sort for Factor 2 suggested a group of individuals who have found receiving the diagnosis more distressing and traumatic, with a focus on the hardship and difficulties associated with it. It is something they cannot change and will be with them forever, as one individual described it, *'It is a prison sentence with no chance of parole'*. This position is similar to one of the autobiographical accounts discussed in chapter two where initially the diagnosis was not accepted (Purkis, 2006).

Two individuals who had loaded significantly onto this factor had received their diagnosis over six years ago, and both had described experiencing depression during this time, suggesting that for some this understanding may be long-term. It is possible that those who conceptualise Asperger's Syndrome and High Functioning Autism in this way may be at greater risk of more negative outcome (Portway & Johnson, 2005). The links between how the diagnosis is understood, acceptance and mental health difficulties, in particular depression, warrants further exploration.

Both factors 3 and 4 presented a less coherent picture of their understanding and acceptance of Asperger's Syndrome and High Functioning Autism. While individuals loading significantly onto Factor 3 indicated a strong acceptance of their diagnosis, it seemed it had been a difficult process which was potentially still ongoing. Both individuals loading significantly on Factor 3 had received their diagnosis in the last two years, which is relatively recent. There is an expression of shame and reluctance to share the diagnosis with even the closest family members that suggested they had not quite made their minds up about it yet. For Factor 4, although both individuals stated they were not disagreeing with their diagnosis, they presented a neutral position on their agreement with it. At the same time they focused more on how they could change and reduce the associated difficulties.

It is possible that with factors 1 and 2 we see an end point of a process of adjustment and acceptance, but that individuals loading onto factors 3 and 4 are still moving through such a process. We can make a judgement on whether we believe factor 1 to represent a more adaptive representation of Asperger's Syndrome and High Functioning Autism. It is certainly consistent

with the authors own view[32], and the acknowledgment of the advantages as well as the difficulties is consistent with the desired outcome of many post-diagnostic support processes (Attwood, 2006; Gray, 1996; Vermeulen, 2001).

Factor 1 is characterised by individuals who had sought out their diagnosis only as clarification of their own conclusions. It could be hypothesised that there is something unique about the process of discovering Asperger's Syndrome and High Functioning Autism by one's self that makes this acceptance easier. The process of diagnosis of any condition, be it associated with physical or mental health, is based on finding explanations for problems, but do we want to conceptualise Asperger's Syndrome and High Functioning Autism as problem? Perhaps a process of diagnosis that mirrored that of self-discovery would aid individuals in their acceptance.

8.2.2 Consequences of diagnosis

All participants had in some way been searching for explanations for why they felt disconnected or different from other people. This ranged from personal investigation through to seeking help from psychiatric services to find explanations and overcome mental health difficulties. Within the Q-set there were statements that reflected the immediate reaction to the diagnosis, the personal consequences that it had for an individual, and the more practical results.

The overall understanding presented in Factor 1 indicated that the diagnosis provided people with answers and explanations for difficulties in the past,

[32]Prior to conducting the data collection stage of the study the author completed a Q-sort herself, this is commonly done to illustrate the bias held by the researchers (Watts & Stenner, 2005). The author's standpoint is most congruent with that of Factor 1, with an understanding that is focussed upon the positive consequences of diagnosis and the skills and strengths an individual holds, within a framework of difference rather than deficit.

and that this had given them greater control allowing them to move on with their lives. Whereas for Factor 2 although there is an indication that some answers to previous difficulties are provided, this does not give control or help a person to have a new beginning. For Factor 1 as we have discussed there appeared to be an acceptance of both the positive and negative aspects of Asperger's Syndrome or High Functioning Autism, whereas for Factor 2 there was greater focus on the negatives. It is possible that when Asperger's Syndrome is viewed in a positive frame the diagnosis can be liberating, whereas when only the negatives are identified with this liberation is absent. This is congruent with the short and long term risks for individuals with Asperger's Syndrome outlined by Portway and Johnson (2005).

Factor 3 like Factor 1 emphasised the answers and explanation that the diagnosis provided, but at this point it has not allowed the individual to seize control or move forward. It is the only factor to strongly express a sense of relief associated with the diagnosis, possibly this related to the fact that at the time of their diagnosis they were seeking out psychiatric support and had never considered Asperger's Syndrome or High Functioning Autism as an explanation. Factor 4 paid more attention to the practical support and potential of therapeutic interventions to bring about change. This was coherent with the belief in change and improvement associated with these individuals' understanding of Asperger's Syndrome and High Functioning Autism.

8.2.3 Theoretical conceptualisation

The findings support those from qualitative studies discussed in chapter two, indicating that Asperger's Syndrome and High Functioning Autism are

conceptualised in different ways by those diagnosed, for instance as a disability, a difference, or an advantage (Cousins, 2001; Molloy & Vasil, 2004; Punshon, 2006).

Factors 1 and 2 clearly attach themselves to specific, albeit divergent, conceptualisations. Factor 1 endorses the understanding that Asperger's Syndrome and High Functioning Autism are differences, rejecting any indication that it is a disability, deficit or impairment. It is the only factor to agree that having Asperger's Syndrome and High Functioning Autism can be advantageous, giving originality of ideas and being beneficial for certain areas of work. Factor 4 also showed agreement with the difference conceptualisation, emphasising the biological basis and the potential variability of severity between people.

In contrast, Factor 2 indicated an almost opposite understanding, being the only factor to agree with the view that it is a lifelong disability and impairment. It is plausible to suggest that an acceptance of Asperger's Syndrome and High Functioning Autism that acknowledges both positive and negative aspects is more concordant with a theoretical conceptualisation based upon an awareness of difference. Whereas, a view of Asperger's Syndrome and High Functioning Autism which only focuses on the disadvantages more closely links with a disability or impairment view. The disability understanding has already been suggested to be associated with a more negative view of Asperger's Syndrome (Aylott, 2000).

Factor 3 absolutely dismissed the understanding that Asperger's Syndrome and High Functioning Autism are psychiatric conditions or should be

understood within an illness model. However, these individuals did not appear to strongly endorse another framework for conceptualisation. Neither of the individuals loading significantly onto this factor were in receipt of support at the time of participation or following their diagnosis, and may not have had much scope for obtaining information or discussing alternative conceptualisations. This lack of framework for understanding Asperger's Syndrome and High Functioning Autism may be linked to their expressed confusion about themselves and the difficulty they expressed with accepting their diagnosis.

There is less evidence for the advantage framework (Molloy & Vasil, 2004; Punshon, 2006), with only Factor 1 indicating advantages associated with having either Asperger's Syndrome or High Functioning Autism. It may be that difference and advantage frameworks are too closely aligned, and that the Q-sort was not sensitive enough to find differences. Additionally, there may be personal factors e.g. work/academic achievement, which makes individuals more likely to endorse the advantage viewpoint. We must consider the importance of experiences prior to diagnosis (e.g. peer relationships, bullying) on the beliefs held about Asperger's Syndrome (Punshon, 2006), it was beyond the scope of this study but future research would be valuable into personal factors associated with different viewpoints.

8.3 Successes and limitations of the study

The evaluation and ranking of a set of fifty-two cards requires advanced cognitive skills, including executive functioning abilities i.e. planning, organisation, shifting attention. Individuals with Asperger's Syndrome and High Functioning Autism can have difficulties with executive functions

(Attwood, 2007). As such the Q-sorting process was presented in a highly structured visual format and participants given time and opportunities for breaks. The Q-sorting process was based upon participants freely sorting the cards into a quasi-normal fixed distribution, where a specific number of statements must be assigned to each rank. Although the free sort structure may have provided greater freedom of expression for participants, it was evident during the sorting process that a number of participants would have struggled to make sorting decisions without the imposed structure. With the support of the structure everybody completed the sort successfully; the structure could therefore be seen as a strength of the design allowing a greater number of individuals to successfully participate.

One of the associated features of Asperger's Syndrome and High Functioning Autism, even at a high level of cognitive functioning is echolalia (Gillberg, 2002). It is possible that qualitative studies with adults with Asperger's Syndrome may be made more problematic due to this factor. As a gauge of whether the study was representing what individuals truly believed or was simply a repetition of others' understanding, they were asked following completion whether they had sorted the statements based upon what they believed or on what others had told them. All but one of the participants indicated that it was based upon their beliefs. Those that indicated it was not explained that they regarded some statements as facts (e.g. *AS/HFA is not caused by a persons upbringing or their social circumstances*) which they had gathered from professionals and personal reading. This could be interpreted as part of the desired process of information gathering and sense-making (Cousins, 2001; Molloy & Vasil, 2004, Punshon, 2006). All of the participants said that their sort represented what they currently

believed about Asperger's Syndrome and High Functioning Autism. To suggest that the sorts were, simply a result of echolalia would therefore be in direct opposition to the indication of the participants.

The multi-stage nature of the study and the time frame for completion meant that time was always going to be in short supply. Regardless of these time pressures certain processes were immutable. Primarily, it was essential that the ethical rigour of the study was assessed and monitored and NHS ethical and Research and Development requirements adhered to at all times. The fact that the study involved two stages, the first stage to produce statements that would be presented to participants at the second stage, led to separate requirements. Unfortunately, prior to starting any aspect of the study the process through which multi-site Research & Development approval is received was delayed, this led to the author making the decision to not complete the focus group with professional members of the locality diagnostic service which had been planned as part of the first stage of the study. Assumptions were made that the views reflected by these individuals would be captured through the thorough review of the academic literature that had been completed for statement development, however, it is not possible to ensure that this is the case.

A key requirement of the ethics process for the second stage was the review of the statement set by the entire ethics committee following its development and before recruitment occurred for the Q-sorting phase. Regrettably, the resolution of this process was delayed by the ethics service leaving only six weeks remaining for recruitment and data collection. Such delays are a common occurrence in research and must be accepted and worked through,

however for a study defined by academic deadlines it can be limiting. It placed restrictions on the number of participants it was possible to meet with during this time, although the author made every attempt to meet with all interested parties.

When designing the study it was hoped to recruit between 40 and 60 participants, as some papers have recommended this number for publication of Q-methodological studies (Stainton Rogers, 1995). However, others argue it is not necessary to have such a large number of participants to establish a reliable factor structure and Q-methodology was designed for small scale analysis (Watts & Stenner, 2005). Although a larger number of participants would allow the findings from this study to be elucidated further, the number of participants recruited here is similar to other published Q-methodological studies (e.g. Jones *et al.*, 2003).

There were number of points within the process of statement collection and selection where bias may have been introduced. As discussed in Chapter 5 the focus group with people with a diagnosis of Asperger's Syndrome or High Functioning Autism carried out in the statement development phase actually included a number of adults without a formal diagnosis. This was due to the limited number of available participants and the author's wish not to compromise the number of participants available to complete the Q-sort. It is likely that these 'self-diagnosed' individuals identified with the positive characteristics of the diagnosis which may have contributed to an overly positive Q-set. The author aimed to counteract this in the later statement selection process where the focus was on selecting a balance of positive and negative statements.

Secondly, the process of categorisation of the statements was completed primarily by the author and only subsequently reviewed by members of the research team. This may have introduced some unidentified bias into the statement selection. If the study was to be repeated a more rigorous method to categorise the concourse and extract the statements would be used.

Additionally the author was responsible for the interpretation of the factors extracted through the Q-factor analysis. However, it must be acknowledged that other researchers may interpret the findings in different ways. A useful part of the Q-methodological process is the validation of the interpretations by the participants, due to the timescale of the study this has not been possible, however, it is hoped to complete this following submission of the study.

Finally, as discussed in the results section both factors 3 and 4 only had two participants loading significantly onto them. The author cautioned that these factors should be considered tentatively but included them as possible viewpoints which may facilitate further discussion. Generalisability of both these factors is limited and the coherence of their interpretations may have limited stability should additional participants be recruited. It may be that these factors are most useful for provoking further questions but not in offering explanations.

8.4 Clinical implications

One participant made a comment that the information one is given at the time of diagnosis is of utmost importance. During the course of the research project a number of other participants referred back to things that they were

told when they went through the diagnosis process. The findings highlighted the different conceptualisations an individual can come to, some of which may be more adaptive e.g. Factor 1. As discussed in chapter one the professional understanding of Asperger's Syndrome and High Functioning Autism is an ever developing field, which is weighed down by confusion. This study lends support to presenting an understanding which is based upon a balanced person-centred view of advantages and difficulties, within a framework of difference. It is important that diagnosticians are aware of their role in helping people understand and conceptualise Asperger's Syndrome and High Functioning Autism.

A number of participants commented on enjoying the process of sorting the statements, finding it particularly useful to have the space to order their thoughts. A Q-sorting process, which is based upon a non-judgemental examination of an individual's conceptualisation of Asperger's Syndrome or High Functioning Autism, may be a useful addition to a therapeutic assessment. By its very nature the Q-sort places the individual in the role of the expert, placing value on their understanding and providing the clinician with an overview of their standpoint. It provides opportunities for psycho-education and introduces different frameworks for understanding without imposing them on individuals, encouraging them to make their own evaluations. The usefulness of the Q-sort for encouraging a collaborative, non-confrontational way of working within therapy has been suggested for working with other client groups, including individuals who hear voices (Jones *et al.*, 2003).

Again similar to the implications suggested by the Q-methodological study with voice hearers (Jones *et al.*, 2003), the emergent factors gained through the process could be useful for tailoring interventions (Roth & Fonagy, 2005). For instance, rather than dismissing and attempting to modify an individuals' well-accepted understanding of Asperger's Syndrome and High Functioning Autism as being a lifelong disability, it may be more useful to support them to develop coping strategies to overcome these difficulties, perhaps within a solution-focussed model (Bliss & Edmonds, 2008). Consequently increasing their self-efficacy through the experience of overcoming the characteristics they perceive as disabling.

8.5 Future research

This study has tentatively raised the suggestion that certain understandings of Asperger's Syndrome and High Functioning Autism may leave individuals more susceptible to developing depression. Future quantitative research would be usefully conducted into establishing whether there are links between beliefs held, adjustment and the experience of mental health difficulties. This would be particularly useful due the predictive power it may hold for identifying vulnerable individuals who may require a longer period of post-diagnostic support. Additionally, it is possible that a longitudinal study focusing on change in understanding over time following diagnosis may allow an in depth examination of the process of adjustment, perhaps initially at the level of a single case.

The statements developed for the Q-sort could usefully be applied to the development of a measure of adjustment to diagnosis of Asperger's Syndrome or High Functioning Autism. The development of such a tool

would be invaluable for clinicians working with individuals post-diagnostically, particularly for identifying those at risk of developing mental health difficulties.

This study very specifically focuses on those diagnosed in adulthood, a comparison study with those diagnosed in childhood who are now adults would be of great interest. Additionally future research could explore in more depth the relationship between personal factors (e.g. work/academic achievement, relationships, early life experiences) and conceptualisation of Asperger's Syndrome and High Functioning Autism. This would again be of great interest due to the predictive power it would have for identifying vulnerable individuals.

8.6 Conclusions

This study successfully builds upon the current qualitative research completed into the experience of receiving a diagnosis of Asperger's Syndrome or High Functioning Autism in adulthood. It focuses its attention on one particular aspect of this experience, the beliefs individuals hold about Asperger's Syndrome and High Functioning Autism. This aspect was of particular interest due to the suggested links it has with post-diagnostic identity development and adjustment (Cousins, 2001; Molloy & Vasil, 2004; Punshon, 2006). Four distinct constellations of understanding were identified and interpreted, differences between these factors were discussed relating to 'acceptance and adjustment', 'consequences of diagnosis' and 'theoretical conceptualisation'.

The findings from the study begin to give us a greater insight into the different ways in which an individual constructs their understanding of diagnosis. It encourages us to ask questions about the relative value of different conceptualisations of Asperger's Syndrome and High Functioning Autism, for promoting adjustment and acceptance. The importance of answering these questions is defined by the implications it would have for identification of individuals who may require additional support to help them make sense of a complicated and at times confusing condition.

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APPENDICES

APPENDIX 1.1:

Asperger's Syndrome Diagnostic Criteria

(Gillberg & Gillberg, 1989; Gillberg, 1991)

Gillberg's – Criteria for Asperger's disorder

1.Severe impairment in reciprocal social interaction (at least two of the following)
(a) inability to interact with peers
(b) lack of desire to interact with peers
(c) lack of appreciation of social cues
(d) socially and emotionally inappropriate behavior

2.All-absorbing narrow interest (at least one of the following)
(a) exclusion of other activities
(b) repetitive adherence
(c) more rote than meaning

3.Imposition of routines and interests (at least one of the following)
(a) on self, in aspects of life
(b) on others

4.Speech and language problems (at least three of the following)
(a) delayed development
(b) superficially perfect expressive language
(c) formal, pedantic language
(d) odd prosody, peculiar voice characteristics
(e) impairment of comprehension including misinterpretations of literal/implied meanings

5.Non-verbal communication problems (at least one of the following)
(a) limited use of gestures
(b) clumsy/gauche body language
(c) limited facial expression
(d) inappropriate expression
(e) peculiar, stiff gaze

6.Motor clumsiness: poor performance on neurodevelopmental examination

(All six criteria must be met for confirmation of diagnosis.)

(Gillberg_& Gillberg, 1989; Gillberg, 1991).

APPENDIX 1.2:

Asperger's Syndrome Diagnostic Criteria

(Szatmari et al, 1989)

Szatmari, *et al.* - Diagnostic criteria for Asperger's Syndrome

1. Social isolation (at least two of the following):
a. no close friends
b. avoids others
c. no interest in making friends
d. a loner

2. Impaired social interaction (at least one of the following):
a. approaches others only to have own needs met
b. clumsy social approach
c. one-sided responses to peers
d. difficulty sensing feelings of others
e. indifference to the feelings of others

3. Impaired non-verbal communication (at least one of the following):
a. limited facial expressions
b. impossible to read emotions through facial expression of the child
c. inability to convey message with eyes
d. avoids looking at others
e. does not use hands to aid expression
f. large and clumsy gestures
g. infringes on other people's physical space

4. Speech and language peculiarities (at least two of the following):
a. abnormalities of inflection
b. over-talkative
c. non-communicative
d. lack of cohesion to conversation
e. idiosyncratic use of words (uses words in a different way then what they would normally mean)
f. repetitive patters of speech

(Szatmari *et al.,* 1989)

APPENDIX 1.3:

Asperger's Syndrome Diagnostic Criteria

(APA, 1994)

DSM-IV – Diagnostic criteria for Asperger syndrome

A. Qualitative impairment in social interaction, as manifested by at least two of the following:

1. marked impairments in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction
2. failure to develop peer relationships appropriate to developmental level
3. a lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g. by a lack of showing, bringing, or pointing out objects of interest to other people)
4. lack of social or emotional reciprocity

B. Restricted repetitive and stereotyped patterns of behavior, interests, and activities, as manifested by at least one of the following:

1. encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus
2. apparently inflexible adherence to specific, nonfunctional routines or rituals
3. stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole-body movements)
4. persistent preoccupation with parts of objects

C. The disturbance causes clinically significant impairment in social, occupational, or other important areas of functioning

D. There is no clinically significant general delay in language (e.g., single words used by age 2 years, communicative phrases used by age 3 years)

E. There is no clinically significant delay in cognitive development or in the development of age-appropriate self-help skills, adaptive behavior (other than social interaction), and curiosity about the environment in childhood

F. Criteria are not met for another specific Pervasive Developmental Disorder or Schizophrenia

(APA, 1994)

APPENDIX 1.4:

Asperger's Syndrome Diagnostic Criteria

(WHO, 1993)

ICD-10 - Diagnostic Criteria for Asperger Syndrome

1. There is no clinically significant general delay in spoken or receptive language or cognitive development.

Diagnosis requires that single word should have developed by 2 years of age or earlier and that communicative phrases be used by 3 years or earlier. Self-help skills, adaptive behavior and curiosity about the environment during the first three years should be at a level consistent with normal intellectual development. However, motor milestones may be somewhat delayed and motor clumsiness is usual (although not a necessary diagnostic feature). Isolated special skills, often related to abnormal preoccupations are common, but are required for diagnosis.

2. There are qualitative abnormalities in reciprocal social interaction in at least two of the following area's:

a. Failure adequately to use eye-to-eye gaze, facial expressions, body posture and gesture to regulate social interaction.

b. Failure to develop (in a manner appropriate to mental age, and despite ample opportunities) peer relationships that involve a mutual sharing of interests, activities and emotions.

c. Lack of social-emotional reciprocity as shown by an impaired or deviant response to other people's emotions, or lack of modulation of behavior according to social context; or a weak integration of social; emotional, and communicative behaviors.

d. Lack of spontaneous seeking to share enjoyment, interests, or achievements with other people(e.g. lack of showing, bringing or pointing out to other people objects of interest to the individual).

3. The individual exhibits an unusually intense, circumscribed interest or restricted, repetitive, and stereotyped patterns of behavior, interests, And activities in at least two of the following:

a. An encompassing preoccupation with one or more stereotyped and restricted patterns of interests that are abnormal in their intensity and circumscribed nature though not in their content or focus.

b. Apparent compulsive adherence to specific, non-functional routines or rituals

c. Stereotyped and repetitive motor mannerisms that involve either hand-or finger-flapping or –twisting, or complex whole-body movements

d. Preoccupations with part-objects or non-functional elements of play materials(such as their odour, the feel of their surface, or the noise or vibration that they generate.

(WHO, 1993).

APPENDIX 5.1:

REC letter outlining required amendments

APPENDIX 5.2:

Documents in evidence of ethical/
Research & Development approval

APPENDIX 5.3:

Complete copy of concourse *(305 statements)*

Individual Statements	Book	Article	Media	Internet resource	Focus Group
IMMEDIATE EMOTIONAL IMPACT/REACTION					
Gaining a diagnosis of AS/HFA is a relief (here is an explanation of why some things are so difficult)	Coming Out AS Dinah Murray; Tim Page; Molloy & Vasil (2004)	Aylott (2000); Punshon (2006)		Amy (NAS website 2008); Mahari (2005; 2005b)	
Gaining a diagnosis of AS/HFA is a positive experience/happy experience	Coming Out AS L. Holliday Willey	Punshon (2006); Sperry & Mesibov (2005)			
Gaining a diagnosis of AS/HFA allows you to understand yourself better	Coming Out AS Dinah Murray; Molloy & Vasil (2004)				
Gaining a diagnosis of AS/HFA helps you discover who you are and why you are as you are				Mahari (2005)	
Gaining a diagnosis of AS/HFA helps you to make sense of previously puzzeling behaviour/provide a framework	Coming Out AS L. Holliday Willey; Molloy & Vasil (2004)	Punshon (2006)			Yes
Gaining a diagnosis of AS/HFA gave explanations for unsual characteristics or peculiarities/answers to previous difficulties/puts behaviour in different context	Finding a different kind of normal (Purkis); Pretending to be normal (Holliday Willey); Molloy & Vasil (2004)	Punshon (2006)		Amy (NAS website 2008)	
Gaining a diagnosis of AS/HFA explains why I do things that normal people would not					Yes
Gaining a diagnosis of AS/HFA is an embarrassment as you are different	Finding a different kind of normal (Purkis)			Mahari (2004)	
I am comfortable with my diagnosis of AS/HFA	Finding a different kind of normal (Purkis)				

I am not ashamed of having a diagnosis of AS/HFA	Finding a different kind of normal (Purkis)			Colin Freeman (Asperger East Anglia Website)	
Gaining a diagnosis of AS/HFA helps you to fit into the world	Finding a different kind of normal (Purkis)				
Gaining a diagnosis of AS/HFA gave confidence to openly discuss oneself and ones difficulties	Pretending to be different (Holliday Willey)				
Gaining a diagnosis of AS/HFA put an end to pretending to be normal that had been there all my life	Pretending to be different (Holliday Willey)				
Gaining a diagnosis leads to a mixed reaction/emotions (mixture of positive and negative)	Molloy & Vasil, 2004	Punshon (2006)		University of Sheffield Autism Centre (PJ); Amy (NAS website 2008)	
Gaining a diagnosis leads to a wide range of feelings				Mahari (2005; 2005b)	
Gaining a diagnosis of AS/HFA is like an awakening/realisation/liberation					Yes
Gaining a diagnosis is a new beguinning/born again/growing up again				University of Sheffield Autism Centre (PJ); Andre John Baptiste (NAS website 2008)	Yes
Gaining a diagnosis is a new identity				University of Sheffield Autism Centre (PJ)	
Gaining a diagnosis gives you freedom					Yes
Gaining a diagnosis is like being 'hit for six'				University of Sheffield Autism	

				Centre (PJ)	
Gaining a diagnosis of AS/HFA is an angry experience (about time lost)/enraged		Punshon (2006); Sperry & Mesibov (2005)			
Gaining a diagnosis of AS/HFA makes you feel annoyed as you feel to blame for the diagnosis	Rice (1999)				
Gaining a diagnosis of AS/HFA is frustrating				Mahari (2005b)	
Gaining a diagnosis of AS/HFA is like experiencing a loss/grief		Punshon (2006)		Mahari (2004; 2005; 2005b)	
Gaining a diagnosis makes you feel sad about the time lost when you did not have the diagnosis		Punshon (2006)			
I do not accept my diagnosis of AS/HFA	Finding a different kind of normal (Holliday Willey); Vermeulen (2001)	Shore (2006)			
Gaining a diagnosis of AS/HFA gives you control over your life				Andre John Baptiste (NAS website 2008)	
Gaining a diagnosis allows you to move on from difficulties in the past				Amy (NAS website 2008)	
Gaining a diagnosis helps you to see that you are not alone/there are others like you	Tim Page			Amy (NAS website 2008)	
Having AS/HFA is something to be proud of/ I'm proud of having AS/HFA			You Tube (AS: A positive perspective, Chris Walker,	Amy (NAS website 2008); Colin Freeman (Asperger East Anglia Website)	

			31.7.08)		
Gaining a diagnosis helps you to change your behaviour		Katz & Zemishlany (2006)			
Gaining a diagnosis of AS/HFA gives you an objective explanation of your strengths and weaknesses	Tim Page				
There are advantages as well as disadvantages to having AS/HFA / positives and negatives	Tim Page			Colin Freeman (Asperger East Anglia Website)	
Gaining a diagnosis of AS/HFA causes pain				Mahari (2004)	
Gaining a diagnosis of AS/HFA brings tears				Mahari (2004)	
You need time and space to accept the diagnosis				Mahari (2004)	
There is life after an AS/HFA diagnosis in adulthood				Mahari (2004)	
Having AS/HFA does not mean that you are less than other people				Mahari (2005)	
Knowing that you have AS/HFA is difficult				Mahari (2005)	
Gaining a diagnosis of AS/HFA as an adult leaves you feeling hopeless				Mahari (2005)	
Gaining a diagnosis of AS/HFA leaves you feeling overwhelmed				Mahari (2005)	
Gaining a diagnosis of AS/HFA means you are stuck where you are, it is the end of the story/it is a dead end				Mahari (2005)	
My entire destiny is ruled by having AS/HFA				Mahari (2005)	
Gaining a diagnosis of AS/HFA makes you feel alienated and lost				Mahari (2005b)	

Gaining a diagnosis of AS/HFA makes you feel depressed				Mahari (2005b)	
Gaining a diagnosis of AS/HFA is a negative thing		Sperry & Mesibov (2005)			
Gaining a diagnosis of AS/HFA means you are stereotyped as being a failiure		Sperry & Mesibov (2005)			
Gaining a diagnosis is empowering and gives confidence					Yes
Understanding AS/HFA makes experiences associated with having it less threatening					Yes
AS/HFA is who I am					Yes
It is useful to have the AS/HFA label (something identifiable)					Yes
Having the AS/HFA label may be negative (jusficatition for discounting what people think)					Yes
Gaining a diagnosis of AS/HFA is a process of discovery					Yes
Gaining a diagnosis of AS/HFA is like being asked to take part in something good					Yes
Having AS/HFA means you look at the world differently, it allows you to come up with things that nobody else can.			You Tube (Tom Heinzman 8.10.07)		
Having AS/HFA gives you the ability to think differently to people who don't have AS/HFA			You Tube (Tom Heinzman 8.10.07)	Autistic Advocacy (Frank Klein)	

AS/HFA is different for everybody who has it			You Tube (I'm Autistic, 11.4.07)		
If you have AS/HFA it turns socialising into an elabourate acting game/have to put an act on to be accepted			You Tube (I'm Autistic, 11.4.07)	ASSGO	
Having AS/HFA means that you have to pretend to be normal	Pretending to be different (Holliday Willey); Molloy & Vasil (2004)				
Having AS/HFA does not mean you are different, it means that you are special			You Tube (AS: A positive perspective, Chris Walker, 31.7.08)		
Nobody can tell by looking at you that you have AS/HFA, this can be a problem			You Tube (In My Mind, Alex Olinkaweitz, 29.3.07)		
I wouldn't have achieved the things I have without AS/HFA, it gave me a passion for my interests			You Tube (Documentary about AS, 13.5.07)		
Gaining a diagnosis of AS/HFA made life easier			You Tube (Documentary about AS, 13.5.07)		
Gaining a diagnosis of AS/HFA helped me			You Tube		

to get to know myself better			(Documentary about AS, 13.5.07)		
Having AS/HFA means that I am unique			You Tube (Documentary about AS, 13.5.07)		
Gaining a diagnosis of AS/HFA meant I stopped comparing myself to other people			You Tube (Documentary about AS, 13.5.07)		
Diagnosis was a relief, as it allowed me to finally understand all that was difficult and painful about my life				Mahari (2004b)	
Diagnosis was a nightmare, as I had to understand all that I had suffered in my life without fully understanding why				Mahari (2004b)	
People with AS/HFA are innovators, providing valuable insight into the world			New York Times (20.12.04)		
I like my AS/HFA				Autistic Advocacy (Frank Klein)	
AS/HFA is more than just a condition in a medical book, it is part of who a person is				Autistic Advocacy (Frank Klein)	
I would not be me if the AS/HFA was not there				Autistic Advocacy (Frank Klein)	
the biggest disability people with AS/HFA is being in such a small minority				Autistic Advocacy (Frank Klein)	
There is nothing wrong with thinking differently about the world				Autistic Advocacy (Frank Klein)	

Having AS/HFA means that you are better off in some ways than people who don't have AS/HFA				Autistic Advocacy (Frank Klein)	
A cure should be found for AS/HFA				Autistic Advocacy (Frank Klein)	
If you have AS/HFA you need to erect defensive armour to protect yourself from the NT world				Autistic Advocacy (Frank Klein)	
I prefer the way people with AS/HFA think, it is more honest, straightforward and logical				Autistic Advocacy (Frank Klein)	
Having AS/HFA is not a curse				Autistic Advocacy (Frank Klein)	
AS/HFA makes it harder to live in the world				Autistic Advocacy (Frank Klein)	
It is not impossible to live in the world if you have AS/HFA				Autistic Advocacy (Frank Klein)	
AS/HFA makes people more creative, due to a strong drive to analyse detail				Whats AS Done for us (BBC News Magazine, 2.6.04)	
AS/HFA is a hard condition to live with				ASSGO	
You can lead an enjoyable and fullfilling life with AS/HFA, but it may be different from other people				ASSGO - Tony Attwood	
Being diagnosed with AS/HFA was the best thing that ever happened to me	Molloy & Vasil, 2004			ASSGO - Alyson Bailey	
Being diagnosed with AS/HFA has meant that I am free to be my true self				ASSGO - Alyson Bailey	

It is societies lack of knowledge about AS/HFA that is the problem, not people with AS/HFA				ASSGO - Alyson Bailey	
Many difficulties people with AS/HFA face are due to society rather than the condition itself			Guardian (7.8.07)		
Our symptoms of AS/HFA are in fact ourselves not some unfortunate illness				ASSGO - Alyson Bailey	
Gaining a diagnosis of AS/HFA is devastating, because it is incurable				ASSGO - Emma Thomson	
Having AS/HFA means that all my life I am going to have this thing that make me odd and different from everybody else				ASSGO - Emma Thomson	
Having AS/HFA makes you nearly normal/ you are almost the same as normal people	Molloy & Vasil, 2004			ASSGO - Emma Thomson	
I get fed up of being an AS/HFA, sometimes I wish I could run away from it.				ASSGO - Emma Thomson	
I am odd because I have AS/HFA				Colin Freeman (Asperger East Anglia Website)	
AS/HFA is part of your personality				Colin Freeman (Asperger East Anglia Website)	
Gaining a diagnosis of AS/HFA can hold you capative to a stereotype and hinder the process of self-discovery			Limor Gal (Haaretz.com News)		
AS/HFA is an integral part of a my life experience, personality and world view			Limor Gal (Haaretz.com News)		

Having AS/HFA is a strength rather than a disability			Guardian (7.8.07)		
AS/HFA is not a pathological condition or a disease, but a way of life that posesses a culture and history all of its own			Guardian (7.8.07)	Wikipedia (Sociological & cultural aspects of Autism)	
Society disables people with an AS/HFA				Wikipedia (AS)	
It can be traumatic having AS/HFA, due to being different				Wikipedia (AS)	
AS/HFA is a valid and unique way of being, which should be embraced and appreciated				Wikipedia (Sociological & cultural aspects of Autism)	
Society has little use for people with AS/HFA				Wikipedia (Sociological & cultural aspects of Autism)	
AS/HFA is a normal part of the diverse human condition				Wikipedia (Sociological & cultural aspects of Autism)	
I am person with AS/HFA, not a person who suffers from AS/HFA				Wikipedia (Sociological & cultural aspects of Autism); NAS Website	
AS/HFA is a very real and very disabling condition				NAS website	
All people with AS/HFA have an				NAS website	

extraordinary ability					
AS/HFA were labels created to explain, understand and identify neurological and behavioural differences	Molloy & Vasil, 2004				Yes
Gaining a diagnosis of AS/HFA helps other people understand who I am	Molloy & Vasil, 2004				
Having a diagnosis of AS/HFA is negative, it means that you are labled, stereotyped and placed in a group (negative)	Molloy & Vasil, 2004				
Gaining a diagnosis of AS/HFA is a shock (disbelief)	Molloy & Vasil, 2004				
People with AS/HFA are almost the same as normal people	Molloy & Vasil, 2004				
People with AS/HFA are all savants	Molloy & Vasil, 2004				
If I could change myself and get rid of my AS/HFA then I would (and opposite)	Molloy & Vasil, 2004				
The good points of having AS/HFA outweigh the bad	Molloy & Vasil, 2004				
There are some difficulties associated with having AS/HFA	Molloy & Vasil, 2004				
Having the diagnosis of AS/HFA gives access to support and benefits	Molloy & Vasil, 2004				
Having AS/HFA sets you apart from others and prevents you conforming to social expectations	Molloy & Vasil, 2004				
All people with AS/HFA are the same	Molloy & Vasil, 2004				
I don't like to tell people I have AS/HFA, it's a personal thing	Molloy & Vasil, 2004				
Not everything about me is to do with	Molloy & Vasil, 2004				

having an AS/HFA					
I was disapointed to find out I had AS/HFA, because it stops you from doing things	Molloy & Vasil, 2004				
Gaining a diagnosis of AS/HFA made me quite confused about myself	Molloy & Vasil, 2004				
I do not think that I am different from people who do not have a diagnosis of AS/HFA	Molloy & Vasil, 2004				
Having AS/HFA means that you are less intelligent and need more help to do things	Molloy & Vasil, 2004				
QUALITY OF LIFE					
Suicidal thoughts are very common for people with AS/HFA		Fitzgerald (2007); Barnhill (2007); Portway & Johnson (2005)			
Having AS/HFA puts you at risk of being depressed/unhappy		Portway & Johnson (2005)			
Having AS/HFA means you may be rejected by others	Coming Out AS Dinah Murray				
Having AS/HFA makes it difficult to make friendships	Coming out AS T. Attwood	Farrugia & Hudson (2006); Tsatsanis (2003)			
You can have a romantic relationship when you have AS/HFA	Coming out AS T. Attwood	Aylott (2000)			
Having AS/HFA means it is difficult to know what other people are thinking	Coming out AS T. Attwood	Farrugia & Hudson (2006)			
Having AS means it is difficult to show affection	Coming out AS T. Attwood				
Having AS/HFA means you are negatively judged by other people	Coming Out AS Dinah Murray				

People with AS/HFA seldom/it is difficult to have partner relationships/get married		Engstrom,Ekstrom & Emilsson (2003); Renty & Roeyers (2006); Tsatsanis (2003); Sperry & Mesibov (2005)			
People with AS/HFA desire social relationships (cannot suggest they have no interested)		Howard, Cohn & Ormond (2006)			
It is hard for people with AS/HFA to develop close spontaneous friendships		Renty & Roeyers (2006)			
People with AS/HFA can learn to relate to others and build relationships				Mahari (2004)	
It is frustrating to not be able to conect with people easily					Yes
It is difficult to make friends when you have AS/HFA			You Tube (Documentary about AS/HFA)		
People with AS/HFA are judged negatively by society		Tantam (2003)			
People with AS/HFA are victimised and misunderstood		Tantam (2003); Portway & Johnson (2005)			
You can belong to a community when you have AS/HFA	Coming out AS T. Attwood				
People with AS/HFA have a lack of normal sociability		Baron-Cohen (2002)			
Having AS/HFA means you must try and 'fit in' with normal society		Howlin (2000); Barnhill (2007)			
Having AS/HFA can lead to you 'living on		Barnhill (2007); Portway &			

the edge of society'/'being an outsider'		Johnson (2005)			
Gaining a diagnosis of AS/HFA helps you to meet others with AS/HFA and gain a social life		Punshon (2006)			Yes
People in society do not adapt to or understand people with a diagnosis of AS/HFA		Punshon (2006)			
Having AS/HFA means that you do not quite 'fit in' with society		Portway & Johnson (2005)			
You must try and look normal to be accepted by society if you have AS/HFA		Portway & Johnson (2005)			
Having AS/HFA impacts on your ability to relate and have healthy successful adult relationships				Mahari (2005)	
People with AS/HFA are at a disadvantage navigating their social worlds		Barnhill (2001)			
Having a diagnosis of AS/HFA can be an obstacle to social interactions		Sperry & Mesibov (2005)			
If you have AS/HFA you may appear to fit in but you do not fit exactly			You Tube (In My Mind, Alex Olinkaweitz, 29.3.07)		
I don't fit in with the group because I have AS/HFA			You Tube (In My Mind, Alex Olinkaweitz, 29.3.07)		
Ostracism is the biggest problem people with AS/HFA face				Autistic Advocacy (Frank Klein)	

Having AS/HFA is isolating/we can feel very lonely and isolated				ASSGO	
If you have AS/HFA you can feel disconnected from other people/you can be cut off from the world				ASSGO	
Having AS/HFA is like being in a bubble, you can see what is going on around you but you never feel involved				ASSGO	
People with AS/HFA should change to fit in with society				Wikipedia (Sociological and cultural aspects of autism)	
You can be autonomous when you have a diagnosis of AS/HFA	Coming Out AS L. Holliday Willey				
You can organise your own life when you have a diagnosis of AS/HFA	Coming Out AS L. Holliday Willey				
With AS/HFA you can attend university/achieve at school	Coming out AS T. Attwood				
It is hard for people with AS/HFA to attend university/college		Renty & Roeyrs (2006); Tsatsanis (2003)			
Having AS/HFA means that you will never achieve as well as your peers	Coming out AS T. Attwood				
Having AS/HFA means you are unlikely to find meaningful/paid employment		Engstrom,Ekstrom & Emilsson (2003); Howlin, Alcock & Burkin (2005); Muller, Schuler, Burton & Yates (2003); Renty & Roeyers (2006); Tsatsanis (2003); Barnhill (2007); Hurlburt & Chalmers (2004)			
Achieving/Living a productive life when you have AS/HFA is harder work and requires persistence		Baron-Cohen (2000); Wing ( ); Howlin (2000); Barnhill (2007)			

It is hard for people with AS/HFA to live independently		Renty & Roeyers (2006)			
It is hard for people with AS/HFA to find jobs to match their ability level		Hurlburt & Chalmers (2004); Sperry & Mesibov (2005)			
There are many advantages of having people with AS/HFA in the workforce		Hurlburt & Chalmers (2004)			
If you find a job which fits with your special interest/skill it can be an advantage					Yes
People with AS/HFA can contribute to society in many ways			Whats AS done for us (BBC News Magazine, 2.6.04)		
Achieving/Living a productive life when you have AS/HFA is harder work and requires persistence			AS BBC News Article (12.2.01)		
With the right support people with AS/HFA can lead full and independent lives				NAS website	
Many people with AS/HFA can learn to cope with their differences, but may continue to need support and encouragement to maintain an independent life				Wikipedia (AS)	
People with AS/HFA have an extensive need for support from families and society		Engstrom,Ekstrom & Emilsson (2003)			
People with AS/HFA do not achieve the levels of social functioning that would be expected from their cognitive and linguistic abilities.		Renty & Roeyers (2006)			
Support from family and friends is important for understanding AS/HFA	Pretending to be normal (Holliday Willey)				

Having AS/HFA makes some things in life somewhat more difficult/complicated				Mahari (2004)	
Receiving a diagnosis of AS/HFA means you can access supports and services		Sperry & Mesibov (2005)			
Having AS/HFA impacts on your self-esteem					Yes
There are things that you can do to manage with AS/HFA					Yes
There are things in life that I will never reach because of having AS/HFA				ASSGO	
There is little hope that a person with AS/HFA will lead an ordinary life	Molloy & Vasil (2004)				
People with AS/HFA are deprived of rights and entitlements		Howlin, Alcock & Burkin (2005)			
THEORIES OF AS/HFA					
Having AS/HFA means you have differences not difficulties/impairments	Coming Out AS L. Holliday Willey			Beardon (2007)	
Having AS/HFA means you have a different way of thinking (cognitive style)	Coming out AS T. Attwood; Molloy & Vasil (2004)	Aylott (2000); Gerland (2000)		ASSGO	Yes
Having AS/HFA is a different way of being in the world/perceiving the world	Molloy & Vasil (2004)	Barnhill (2001); Attwood (1998)		Mahari (2005; 2005b); ASSGO	Yes
A different way of thinking is no better or worse than a non-AS/HFA way of thinking		Baron-Cohen (2002)		Mahari (2005)	Yes
Having AS/HFA means you ARE a problem/are mad/are defective	Coming Out AS Dinah Murray				
Having AS/HFA does not mean you are defective				Mahari (2005b)	
Having AS/HFA means you HAVE a problem	Coming Out AS Dinah Murray	Stoddart (1999)			

People with AS/HFA present with a variety of characteristics (present very differently)/wide range of differences	Pretending to be normal (Holliday Willey)	Lorence (2007); Tantam (2003)		OASIS website	
AS/HFA can range from mild to severe		Lorence (2007)		OASIS website	
AS/HFA is on the higher functioning end of the autistic spectrum		Barnhill (2007)			
AS/HFA is a very complicated condition that affects many aspects of an individuals life		Lorence (2007)			
Having AS/HFA may mean you have specific difficulties with some things but you are not all bad	Coming Out AS Dinah Murray				
Being different is as good as being like everybody else		Aylott (2000)			
Having AS/HFA means you DO NOT live in your own world		Tantam (2003)			
Having AS/HFA means means you live on an island within the sea of the rest of humanity		Tantam (2003)			
Having AS/HFA means you live alongside but distinctly apart from the rest of humanity	Tim Page				
Having AS/HFA means that you live in a different world to other people	Finding a different kind of normal (Purkis)				
AS/HFA are less severe types of autism		Tantam (2003)			
Society put up (social) barriers that hinder people with AS/HFA making sense of the world		Aylott (2000); Tantam (2003)		Beardon (2007)	
It is the interaction between the person with		Renty & Roeyers (2006)			

AS/HFA and the environment not factors within the individual that cause difficulties					
You cannot help having AS/HFA, what matters is what you do with it		Tantam (2003)			
People with AS/HFA are eccentric and odd		Fitzgerald (2007); Lorence (2007)			
AS/HFA is a psychiatric condition		Baron-Cohen (2002)			
AS/HFA is a disorder		Baron-Cohen (2002); Molloy & Vasil (2002)			
AS/HFA is a difference not a disorder/disability		Baron-Cohen (2002)		Beardon (2007); Wikipedia (AS); Wikipedia (Sociological and cultural aspects of autism)	
AS/HFA is a disability (lifelong)	Molloy & Vasil (2004)	Baron-Cohen (2002)		Autistic Advocacy (Frank Klein); NAS website	
AS/HFA is a non-obvious disability (hidden disability)		Portway & Johnson (2005)		NAS Website	
AS/HFA is a handicap/abnormal/ill/deficient/retarded		Baron-Cohen (2002); Stoddart (1999)			
People with AS/HFA show differences because they are impaired		Baron-Cohen (2002)			
AS/HFA appears on a continum which blends seamlessly with normality		Baron-Cohen (2002); Baron-Sohen, Wheelwright, Skinner, Martin & Clubley (2001)			
The differences that people with AS/HFA are on underlying dimensions on which all		Baron-Cohen (2002)			

people vary (systemising & empathising)					
Having AS/HFA means that you are different from the norm (and aware of it)		Barnhill (2007)		Mahari (2004)	
Having AS/HFA means that you are different from other people and there is nothing you can do to change that	Finding a different kind of normal (Purkis)				
Having AS/HFA means you are a member of a strange minority	Finding a different kind of normal (Purkis)				
Everybody with AS/HFA is different but all share points at which they connect	Finding a different kind of normal (Purkis)				
Within the boundaries of AS/HFA there are a wide range of abilities and disabilities	Pretending to be normal (Holliday Willey)				
The world would be a dull place if there were not people with AS/HFA in it	Pretending to be normal (Holliday Willey)/T.Attwood foreword				
Having AS/HFA does not mean you are bad or unable/there is nothing inherently wrong	Pretending to be normal (Holliday Willey)				
Having AS/HFA means you have an advantage over other people		Punshon (2006)			
AS/HFA is the next stage of human evolution		Punshon (2006); Attwood (2006)			
There are no two people with AS/HFA who are the same/ all people are different	Molloy & Vasil (2004)	Asperger; Portway & Johnson (2005); Tantam (2000)		ASSGO	
People with AS/HFA are geniuses		Hough (2006)			
Having AS/HFA means you are weak				Mahari (2004)	
Having AS/HFA means you are vulnerable				Mahari (2004)	
Having AS/HFA means that you are lost/feel lost				Mahari (2004)	

You are still likeable and loveable if you have AS/HFA				Mahari (2004)	
Having AS/HFA bestows upon you gifts and skills that one must celebrate and fullfill their potential with				Mahari (2004)	
AS/HFA is not a mental health issue or illness				Mahari (2005)	
AS/HFA is not something that needs to be fixed or cured				Mahari (2005)	
AS/HFA is a pervasive developmental disorder		Molloy & Vasil (2002)		Mahari (2005)	
Having AS/HFA is not all that you are				Mahari (2005b)	
Having AS/HFA is a gift				Mahari (2005b)	
AS/HFA is a milder form of autism		Barnhill (2001); Ritvo, Ritvo, Guthrie & Ritvo (2008)		NAS website	
AS/HFA is a variant of autism/a sub-category of ASD		Molloy & Vasil (2002)			
AS/HFA is a highly disabling condition		Barnhill (2001); Tantam (1991)			
AS/HFA is a devastating disease		Gerlai & Gerlai (2003)			
People with AS/HFA should be cured and rehabilitated		Molloy & Vasil (2002)			
A diagnosis of AS/HFA is based on the deficits/impairments a person has in certain abilities/characteristics lacking		Molloy & Vasil (2002); Winter-Messiers et al (2007)			
AS/HFA is a neurological difference (as opposed to a medical condition)	Molloy & Vasil (2004)	Molloy & Vasil (2002)	Autistic Advocacy (Frank Klein)		

No gene or discovery of different neurological wiring will wholly explain AS/HFA		Molloy & Vasil (2002)			
AS/HFA is an interesting difference from the neurological norm		Molloy & Vasil (2002)			
AS/HFA does not result from pathological development but are normal traits that have become expressed to an extreme degree in certain individuals		Ritvo et al (2008)			
Having AS/HFA does not mean you are qualitatively different from the rest of the population		Baron-Cohen & Wheelwright (2003)			
Normal is different for everybody in the world		Sperry & Mesibov (2005)			
Having AS/HFA is not your fault/not the fault of the individual with the condition				NAS website	Yes
Having AS/HFA is not a moral failing					Yes
AS/HFA is hereditary					Yes
AS/HFA is affected by how you are brought up and the support and understanding you receive					Yes
AS/HFA does not improve with time				Better Health Channel	
AS/HFA means that there is a slight difference in the construction of the brain				Autistic Advicacy (Frank Klein)	
AS/HFA is an impairment				Autistic Advicacy (Frank Klein)	
AS/HFA causes problems				Autistic Advicacy (Frank Klein)	

By having AS/HFA we may all have some of the same traits, but we are all individuals in ourselves, different personalities, different circumstances and each effected differently.				ASSGO - Alyson Bailey	
AS/HFA is a disorder of personality		Lorna Wing (1991)			
There are weaknesses associated with having AS/HFA, these can be remediated by specific types of therapy				OASIS Website	
AS/HFA manifests itself in eccentric behaviours, rather than pronounced and obvious disability			AS BBC News Article (12/2/01)		
AS/HFA affects people in many different ways and to varying degrees				NAS Website	
AS/HFA is not caused by a persons upbringing or their social circumstances				NAS Website	
AS/HFA is not a disorder, disability or illness but a different and legitimate way of life			Limor Gal (Haaretz.com News)		
AS/HFA is a trait not a disability			Limor Gal (Haaretz.com News)		
People with AS/HFA are part of a minority group, not a group of people who are ill			Limor Gal (Haaretz.com News); Guardian 7.8.07		
AS/HFA is not a disability it is another human variation			Guardian (7.8.07)		
AS/HFA is part of neurodiversity			Guardian		

			(7.8.07)		
AS/HFA is not a disease			New York Times (20.12.04)		
AS/HFA is an alternative form of brain wiring, with its own benefits and drawbacks, rather than a devastating disorder in need of curing			New York Times (20.12.04)		
AS/HFA is not a deviation from the norm that must be treated or cured				Wikipedia (AS)	
AS/HFA is a complex syndrome not a disease which that must be cured				Wikipedia (AS)	
AS/HFA is a mental abnormality, and people cannot be changed or saved	Molloy & Vasil (2004)				
AS/HFA stays with you all through your life, but it just keeps on improving	Molloy & Vasil (2004)				
STRENGTHS					
It is possible to find a niche and flourish with AS/HFA	Coming Out AS Dinah Murray				
AS/HFA is advantageous for some types of work	Coming Out AS Dinah Murray				
It is an asset to have people with AS/HFA in society/are of high value to society	Coming out AS T. Attwood	Barnhill (2007); Winter-Messiers (2007)			
The different way of thinking associated with AS/HFA can be an advantage leading to potential for original thought		Aylott (2000)			
People with AS/HFA have entact and superior systemising ability		Baron-Cohen (2002)			
People with AS/HFA are honest, straight				Beardon (2007)	

talking and genuine					
People with AS/HFA have a great attention to detail				Beardon (2007)	
People with AS/HFA have unique skills/special talents		Baron-Cohen & Klin (2006)			
People with AS/HFA are geniuses		Hough (2006)			
Many of the strengths I have in life are associated with having AS/HFA		Mahari (2005b)			
There are many strengths associated with having AS/HFA		Molloy & Vasil (2002)			
Strengths associated with AS/HFA need to be recognised by those around you					Yes
Having AS/HFA gives you advantages over the NT population					Yes
It is helpful to have people with AS/HFA in society					Yes
DIFFICULTIES					
The different way of thinking associated with AS/HFA can lead to misunderstandings		Aylott (2000)			
In a world where people are expected to be social people with AS/HFA are disabled		Baron-Cohen (2002)			
Being object focused is only a disability in a world where people expect you to be social		Baron-Cohen (2002)			
Having AS/HFA means you are unable to behave in socially desirable ways		Stoddart (1999)			
Having AS/HFA means you are rigid in your thinking		Farrugia & Hudson (2006)			
Having AS/HFA means you are unable to		Farrugia & Hudson (2006)			

learn from your mistakes					
Having AS/HFA means you are unable to cope with being wrong		Farrugia & Hudson (2006)			
Having AS/HFA means you are unable to change your behaviour in response to environmental demands		Farrugia & Hudson (2006)			
Having AS/HFA means you have no understanding whatsoever of the implications and repercussions of your actions		Katz & Zemishlany (2006)			
Having AS/HFA means I have significant difficulties with social relationships			You Tube (Documentary about AS, 13.5.07)		
OTHER					
Having AS/HFA shapes a persons personality	Finding a different kind of normal (Purkis)				
AS/HFA is part of me	Finding a different kind of normal (Purkis)				
I do not wish for a cure for AS/HFA	Pretending to be normal (Holliday Willey)				
Gaining a diagnosis of AS/HFA allows access to support					
Gainiing a diagnosis of AS/HFA allows you to see the positive aspects of getting a diagnosis		Punshon (2006)			
Gaining a diagnosis of AS/HFA earlier in life may have meant avoiding all the suffering and unhappiness		Punshon (2006)			

For success in science and art a dash of autism is essential	Tim Page	Asperger			
Gaining a diagnosis of AS/HFA as an adult is a different kind of a challenge than for those diagnosed as children				Mahari (2004)	

APPENDIX 5.4:

Focus group question sheet

FOCUS GROUP - exploring of the beliefs held about Asperger Syndrome/High Functioning Autism when the diagnosis is received in adulthood.

Outline of Focus Group

A) <u>Introduction</u>

- Recap on project
- Purpose of focus group
- Procedure
- Ground rules
- Any questions?

B) <u>Questions</u> (main)

These are the main questions I will ask, however, I may ask some additional questions.

1. What does having AS/HFA mean to you?
2. How do you feel about having AS/HFA?
3. Are there positive aspects of having AS/HFA?
4. Are there negative aspects of having AS/HFA?
5. Are there any areas of your life that having AS/HFA impacts upon?

C) <u>Conclusion</u>

- Summary
- Thanks
- Debriefing

APPENDIX 5.5:

Focus group participant information sheet & consent form

PARTICIPANT INFORMATION SHEET – 1.2
Focus Group (voluntary agency)

Title: '*What does it mean to me?': A Q-methodological exploration of the beliefs held about Asperger Syndrome/High Functioning Autism when the diagnosis is received in adulthood.*

You are being invited to take part in a research study that is being carried out by Emma Seel, in part fulfilment of a Doctorate degree in Clinical Psychology at the University of Edinburgh.

Before you decide whether you would like to take part, it is important that you understand why the research is being carried out and what it would involve for you. Please take time to read the following information carefully. Talk to others about the study if you wish.

The information sheet has two parts;

- **Part 1**: This tells you about the purpose of the study and what will happen to you if you take part.
- **Part 2**: This gives you more detail about the conduct of the study.

Please read Part 1 first and then continue onto Part 2.

Please ask questions if anything is unclear or if you would like us to provide more information.

Please take time to decide whether or not you would like to take part.

PART 1 of the information sheet:

The Purpose of the study
This study aims to begin to understand what it *means* to people to receive a diagnosis of Asperger Syndrome/High Functioning Autism as an adult. Different people may hold different beliefs or think different things about having Asperger Syndrome/High Functioning Autism.

It is hoped that the study will help professionals who work with people with Asperger Syndrome/High Functioning Autism to better understand what it means to have a diagnosis. The more information professionals have about how people think about their diagnosis, the better able they are to provide the right support.

A range of individuals diagnosed in adulthood will be invited to participate so we can investigate the range of different meanings that are held by different people.

This part of the study is being carried out to gather initial information about the beliefs people hold about Asperger Syndrome/High Functioning Autism. This information will be used to help produce statements about Asperger Syndrome/High Functioning Autism to be used in a further part of the study (more information about this part is available on request).

Why have I been invited?
You are being invited to take part in this study because you are a person who was diagnosed with Asperger Syndrome or High Functioning Autism, or both, during adulthood. We hope to recruit 3-4 people in total.

Do I have to take part?
It is up to you to decide if you want to take part. I (Emma Seel) will describe the study and go through this information sheet with you. I will then give you the information sheet so you can go away and read it again and think about participating.

After no less than 48 hours I will contact you again to ask you if you have made a decision. If you are happy to participate then I will ask you to sign a consent form to show you have agreed to take part.

It is important that you know that you are free to withdraw at any time, without giving a reason. This would not affect the standard of care you receive or access to any services.

What will happen to me if I take part?
The total length of time it takes to participate is **one hour**.

You will only need to meet with me on one occasion for one hour, the meeting will take place at [redacted]

When we meet there will be only one task to complete.

What tasks do I have to do?	How long will it take?
Participate in a group discussion about Asperger Syndrome/High Functioning Autism. The discussion will be about what you feel people with a diagnosis believe about Asperger Syndrome/High Functioning Autism.	60 minutes

What will I have to do?
I will be present throughout the duration of the discussion and will be the facilitator. All participants will meet together for one hour. I will ask some questions about Asperger Syndrome/High Functioning Autism e.g.

- Does having Asperger Syndrome/High Functioning Autism have any negative consequences?
- Does having Asperger Syndrome/High Functioning Autism have any positive consequences?

Everybody will have chance to discuss what they think about the questions. You can contribute as much or as little as you want, that is ok. The discussion **will be audio recorded** to allow me to listen back and make sure I did not miss out any important information.

At the end there will be the opportunity for you to ask any questions or discuss any matters arising from the task.

What are the benefits and possible costs of taking part?
Although there may not be any direct benefit for you, it is hoped that the information gained will be used to educate professionals about what it means to receive a diagnosis of Asperger Syndrome/High Functioning Autism as an adult.

Some people may be distressed about thinking about there diagnosis and they may experience discomfort. If people are distressed at any point and wish to discontinue participation or have a break that is ok.

What if there is a problem?

Any complaint about the way you have been dealt with during the study or any possible harm you might suffer will be discussed. The detailed information on this is given in Part 2.

Will my taking part be kept confidential?
Yes. We will follow ethical and legal practice and all information about you will be handled in confidence. The details are included in Part 2.

If the information in Part 1 has interested you and you are considering participation, please read the additional information in Part 2 before making any decision.

PART 2 of the information sheet:

What will happen if I don't want to carry on with the study?
You can withdraw from the study at any time.

If you do withdraw then all the data that we have collected from you will be destroyed and will not be included in the final analysis. Withdrawing from the study will not affect any care that you receive from the NHS or any voluntary agency.

What if there is a problem?
If you have a concern about any aspect of this study, you can speak to the main researcher, Emma Seel, either [redacted] . She will do her best to answer your questions. If you remain unhappy and you wish to complain formally, you can do this through the NHS Complaints Procedure or through the University of Edinburgh, Details can be obtained from [redacted] or from the [redacted]
.
In the event that something does go wrong and you are harmed during the research and this is due to someone's negligence then you may have grounds for a legal action for compensation against [redacted] or The University of Edinburgh, but you may have to pay your legal costs. The normal National Health Service complaints mechanisms will still be available to you (if appropriate).

Will my part in this study be kept confidential?

We have already said that your participation in the study will be kept confidential and that all the data that is collected from you will not be identifiable. But it is important that you know exactly how this would happen.

What will happen to my data?
The data collected will only be used for this study. Only the main researcher (Emma Seel), the clinical supervisor [redacted] and the academic supervisor [redacted] will have access to the data collected.

Following participation each individual's data will be allocated a number, and will no longer be identified by name. Only the main researcher and the clinical supervisor will have access to the names associated with the specific number. These measures are taken very seriously to protect the anonyminity of the participants.

The audio recordings of the session will be transcribed, and both the audio recording and the transcription will be kept within a locked filing cabinet in NHS property. The data will be kept for 5 years after the study is completed, and then destroyed.

The data will be used to help produce a set of statements about Asperger Syndrome/High Functioning Autism. These will be used in the second part of the study.

What will happen to the results of the research study?
It is intended that the results of the research will be written up for publication in a journal which is aimed specifically at research into Autism Spectrum Disorders. It is hoped that by doing this that the results will be spread widely in the Autistic Spectrum community and to professionals working in this area.

All participants will be sent a written summary of the research findings including all parts of the study.

Who is organising and funding the study?
This study is organised jointly between [redacted] and The University of Edinburgh, and will form part of the academic requirements for the main researcher's (Emma Seel) Doctoral training in Clinical Psychology.

Who has reviewed the study?
All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee to protect your safety, rights, wellbeing and dignity. The [redacted] Research Ethics Committee, which has responsibility for scrutinising proposals for medical research on humans, has examined this proposal and raised no objections from the point of view of medical ethics.

Who can I contact for more information?

If you require further information about research in general then a useful website is INVOLVE (http://www.invo.org.uk/) which promotes public involvement in the NHS.

If you require further specific information about this research project then please contact the main researcher, Emma Seel at [redacted] (Clinical Supervisor) will also be happy to discuss the research on [redacted] .

If you are unhappy with the study and wish to discuss this with someone then any member of the research team will be happy to discuss this with you. Or please refer to the section on problems during research in Part 2 for more information on the complaints procedure.

Thank you for reading this information sheet and considering taking part in the study.

Location: [redacted] *(circle)*

Study: FOCUS GROUP (support group)

Participant Identification Number:

CONSENT FORM – 1.1

Title of Project: What does it mean to me?: A Q-methodological exploration of the beliefs held about Asperger Syndrome/High Functioning Autism when the diagnosis is received in adulthood.

Name of Researcher: Miss Emma Seel

	Please initial box
1. I confirm that I have read and understand the information sheet dated 19/12/07 (version 1.2) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	☐
2. I understand that my participation in this FOCUS GROUP is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.	☐
3. I agree to the FOCUS GROUP being audio recorded. I have been informed that the tapes will not be used for any additional purpose. I understand that the recording will be kept for the duration of the study (12 months) and that the Chief Investigator will then destroy the tapes.	☐
4. I have been informed that only the Chief Investigator (Miss Emma Seel), Academic Supervisor [redacted] and Clinical Supervisor [redacted] will have access to the recordings.	☐
5. I agree to take part in the above study.	☐

_____	_____	_____
Name of Participant	Date	Signature
_____	_____	_____
Name of Person taking consent	Date	Signature

APPENDIX 5.6:

Focus group transcription *(3 page excerpt)*

[RESEARCHER] : Lets set that going again. So we've all had a chance to look at the sheet. I will just move that out of the way of that way.

([RESEARCHER] moves bottle of juice out of way of microphone).

Erm, we've all had a chance to look at the sheet, and we have all had a kind of chance to introduce ourselves.

I don't know whether if I kind of ask the first question really about, what people feel having AS/HFA means to them. I don't know if anybody wants to start…… ?

[Participant 4]: I feel, ….I feel that, I only found about it a few years ago. Although it was mentioned, you know, by a psychologist from the school team. My parents .. Because, because it wasn't noticeable with me because I had a quite high IQ at school, the teachers didn't really have any concerns it was just really the shyness, the lack of eye contact and socialising side of it. But they never really showed any concerns. I think my parents just wanted me to just, um, …. get … get on with it and try and make the best out of myself as I could. You know there have been you know there have been good times and there have been bad times, but since I since I found out, you know, quite a lot of things made sense to me.

You know I found I had some difficulties with some socialising skills, and the clumsiness, although that's getting better I still, I still get myself into a fluster You, you, saw that tonight. You know.

(throughout [RESEARCHER] indicates encouragement with nodding and ums)

[RESEARCHER]: That can happen to all of us…..

[Participant 4]: It's getting easier. But the main problem with me is it affected my self esteem I go around thinking that I 'm not good enough for people you know. Even though there are a lot of people in my life that are encouraging me now. You know I'm happier now than what I ever was. It is still a confidence thing within the inner me, you know, but it is getting better, but I've just got to keep working on that really.

[RESEARCHER]: Um, that's really really great thank you for sharing that [Participant 4]. Is that confidence around, linked to having Asperger Syndrome, or……

[Participant 4]: Um, well I think, I mean its so broad Asperger Syndrome, …..

[RESEARCHER]: Right

[Participant 4]: ……. from what I've researched on it, its you know you can get people that have Aspergers Syndrome, you know, that don't have issues with their confidence. (Hm mm). You know, you know, but you know you can get some people that do (Hm mm). So I think its definitely linked in some way I think, because it doesn't seem, you see there are a lot of positive things happening in my life and obviously there can some times be negative things. And its so hard because I thing again this is to do with the Aspergers Syndrome its like the negatives overlaps all the positives. Even though there's only one negative and you know the rests all positives……

[Participant 6]: Hmm *(nods in agreement)*.

[Participant 4]: …….. its really really hard to keep focused. You need people to say to you know don't focus on that focus on this, believe this, you know, so its just really trying to get that balance.

(HM Mm)

[RESEARCHER]: No that's really great, I heard, you know [Participant 6], …. I heard *([Participant 6] looks a bit flustered, change to whole group focus)*

I was wondering is that something other people agree with? Or?

[Participant 6]: yeh erm *(clears throat)*

[Participant 3]: Erm, sorry sorry were you going to say something?

[Participant 6]: No go ahead.

[Participant 3]: I was going to say I know what mean about what you use the word awakening, realisation, you, it's a relief to suddenly to be able to make sense of things.

[Participant 6]: Ummm

[Participant 3]: And I found my self going through a , erm its almost seems like, it was almost like growing up again. Like going through ….

[Participant 4]: Like being born again sort of thing …

[Participant 6]: yeh, I was thinking of my late teens early twenties, its learning things, that I thought well actually I should have learnt this twenty years ago.

[Participant 4]: Yeh, you just feel if I'd known that, ten years ago

[Participant 3]: Yeh, I mean there is an old saying if I knew now what I knew then, I mean I guess that's an age thing anyway.

[Participant 4]: Then again that was ten years ago, people didn't know that much about it its only recently that people have been taking an interest or studying it. I mean it was, it was just lucky for me that the psychologist I was attending at the time was doing research into it herself otherwise it probably would never have been mentioned. I mean but I have never been formally diagnosed. I didn't get a test it was just an observation from the psychologist who consulted me, who mentioned it might be there. I'm pretty sure it is there, I mean when I go over everything in my head I'm pretty sure it is there.

[Participant 3]: Yes, it's like the jigsaw fits. Some…Once you realise that , your, your, looking into the world, I think we, maybe others don't feel this, but you you realise why you feel detached from things. Because everybody else is in the same goldfish bowl and your looking in. And actually that's a very ….. in ….. what's the word I'm looking for, it gives a lot of freedom.

[Participant 5]: Liberating.

[Participant 3]: Liberating, Thank you. Ha Ha. It's a very liberating experience, erm you don't have to comply anymore.

[Participant 4]: You don't have to justify yourself, you could you know, er just be you and understand yourself a bit better. It's a choice, you know, if you want to socialise you can, if you don't want to socialise you don't have to.

[Participant 3]: *(at same time)* No, you don't. That's right.

[Participant 4]: It's as simple as that.

(few people)

[Participant 5]: Erm I get the sense that we have justified ourselves by knowing ourselves, …. Er…. Empowered by the the serious fact of of being us. And having having never having much confidence in the ordinary world, I think I would say mine has increased certainly by having a scene to lean on.

(Many voices making noises in agreement)

[RESEARCHER]: So, so by having a diagnosis you feel more empowered by …

[Participant 5]: yeh

[RESEARCHER]: You said interestingly that to 'lean on' …

[Participant 5]: That to lean on the social scene of Aspies

[Participant 3]: Yes, because there is there is an alternative 'scene' as you call it. And most of the world probably can't can't see it. Then, there again why would they.

APPENDIX 5.7:

Website listings for statement development

Websites accessed (23/1/08)

http://en.wikipedia.org/wiki/Asperger_syndrome

http://www.nas.org.uk/nas/jsp/polopoly.jsp?d=212

http://www.aspergerfoundation.org.uk/

http://news.bbc.co.uk/1/hi/health/medical_notes/a-b/1166811.stm

http://www.ninds.nih.gov/disorders/asperger/detail_asperger.htm

http://www.udel.edu/bkirby/asperger/aswhatisit.html

http://www.udel.edu/bkirby/asperger/

http://www.users.dircon.co.uk/~cns/

http://www.asperger.org.uk/

http://www.mugsy.org/bishop.htm

http://www.assupportgrouponline.co.uk/

http://www.youtube.com/watch?v=WAfWfsop1e0

http://www.nas.org.uk/

http://www.wired.com/wired/archive/9.12/aspergers_pr.html

http://news.bbc.co.uk/1/hi/magazine/3766697.stm

http://en.wikipedia.org/wiki/High-functioning_autism

http://www.nas.org.uk/nas/jsp/polopoly.jsp?d=1049&a=3337

http://www.phad-fife.org.uk/

http://www.autismuk.com/index6sub.htm

http://www.highfunctioningautism.org/

http://www.answers-about-autism.info/high-functioning-autism-pros-and-cons.html

http://www.youtube.com/watch?v=hBoSxYaWybY

http://www.betterhealth.vic.gov.au/bhcv2/bhcarticles.nsf/pages/Asperger_syndrome_and_adults

http://www.autismlondon.org.uk/what-is-autism/living-with-aspergers.htm

http://www.faaas.org/

http://www.suite101.com/article.cfm/adult_aspergers/106808/1

http://www.reboundtherapy.org/papers/aspergers/diagnosis_of_aspergers_by_tony_attwood.pdf

http://www.bbc.co.uk/dna/h2g2/A10450694

http://www.aspires-relationships.com/articles_as_in_the_military.htm

http://en.wikipedia.org/wiki/Autism

http://www.nas.org.uk/nas/jsp/polopoly.jsp?a=12770&d=567

http://access.autistics.org/information/pdd/hf.html

http://home.att.net/~ascaris1/

APPENDIX 5.8:

Statement selection categories

Please choose the statements you feel best represent the range of statements i.e. select statements which are most different from each other. A guide to the number of statements has been included, however, this is just a guide, if you feel you additional statements are essential please include them. I have given 60 possible selections.

- As a rough guide in the **Emotional Reactions** category, select approximately 5 statements.
- In the **Experiential Reactions** category, select 3 statements.
- As a rough guide in the **Self-understanding** category, select approximately 5 statements.
- In the **Other Understanding** category, select 2 statements.
- In the **Finding Place in World** category select 1 statement.
- As a rough guide in the **Sense of self** category, select approximately 3 statements.
- As a rough guide in the **Relationship with world/society** category, select approximately 3 statements.
- As a rough guide in the **Presentation of AS/HFA category**, select approximately 2 statements.
- As a rough guide in the **Role of AS/HFA within society** category, select approximately 2 statements.
- As a rough guide in the **Social aspects** category, select approximately 5 statements.
- As a rough guide in the **Quality of Life** category, select approximately 5 statements.
- As a rough guide in the **Medical explanation** category, select approximately 5 statements.
- As a rough guide in the **Difference explanation** category, select approximately 5 statements.
- As a rough guide in the **Spectrum Theory** category, select approximately 1 statement.
- As a rough guide in the **Social Theory** category, select approximately 1 statement.
- As a rough guide in the **Personal responsibility** category, select approximately 2 statements.
- As a rough guide in the **Advantage Theory** category, select approximately 1 statements.
- As a rough guide in the **Odd/eccentric theory** category, select approximately 1 statements.
- As a rough guide in the **Thoughts on cure** category, select approximately 2 statements.

- As a rough guide in the **Strengths & Difficulties** category, select approximately 1 statements.
- As a rough guide in the **AS/HFA Community** category, select approximately 1 statements.
- As a rough guide in the **Practical impact/support** category, decide whether you think the statement should be included.
- As a rough guide in the **Living with AS/HFA** category, select approximately 3 statements.

APPENDIX 5.9:

Final statement set

1. Having a diagnosis of AS/HFA is a relief
2. Having a diagnosis of AS/HFA is empowering
3. Having a diagnosis of AS/HFA is like a new beginning to my life
4. Having a diagnosis of AS/HFA means that I am free to be my true self
5. Having a diagnosis of AS/HFA allows me to understand myself better
6. Having a diagnosis of AS/HFA gives me answers to my previous difficulties
7. Having a diagnosis of AS/HFA gives me control over my life
8. Having a diagnosis of AS/HFA allows me to move on from difficulties in the past
9. Having a diagnosis of AS/HFA helps other people understand who I am
10. Having a diagnosis of AS/HFA helps me see that I am not alone and there are others like me
11. I would not be me if the AS/HFA was not there
12. I can belong to a community even if I have a diagnosis of AS/HFA
13. AS/HFA affects people in many different ways and to varying degrees
14. Having AS/HFA is advantageous for some types of work
15. Having AS/HFA means that there is a difference in the construction of your brain
16. Having AS/HFA is a different way of being in the world
17. The difference that I have because of AS/HFA are on underlying dimensions on which all people vary
18. Having AS/HFA allows me to come up with ideas that nobody else can
19. Many difficulties people with AS/HFA face are due to society rather than the condition itself
20. AS/HFA is not caused by a persons upbringing or their social circumstances
21. Having AS/HFA is not my fault
22. Having AS/HFA is a gift
23. Having a diagnosis of AS/HFA does not mean I am part of a group of people who are ill
24. Having a diagnosis of AS/HFA means that I can access supports and services
25. I am likeable and loveable even though I have a diagnosis of AS/HFA
26. AS/HFA will stay with me all through my life
27. I am ashamed of having a diagnosis of AS/HFA
28. Having a diagnosis of AS/HFA makes me angry
29. I feel hopeless about having a diagnosis of AS/HFA
30. It is traumatic having AS/HFA
31. Having a diagnosis of AS/HFA makes me feel confused about myself

32. Having a diagnosis of AS/HFA means that I am labelled, stereotyped and placed in a group
33. Having AS/HFA means that I do not quite fit in with society
34. I feel disconnected from other people, because I have AS/HFA
35. Society has little use for people with AS/HFA
36. Having AS/HFA prevents me from conforming to social expectations
37. I am victimised and misunderstood because I have AS/HFA
38. I am judged negatively because I have AS/HFA
39. Living a productive life when you have AS/HFA is harder work and requires persistence
40. Because I have AS/HFA I have an extensive need for support from my family and society
41. It is difficult to make friends when you have AS/HFA
42. Having AS/HFA means that I will never achieve as well as my peers
43. AS/HFA is an impairment
44. AS/HFA is a psychiatric condition
45. AS/HFA is a lifelong disability
46. AS/HFA is a very complicated condition that affects many aspects of your life
47. There is nothing I can do to change me having AS/HFA
48. AS/HFA is a milder form of autism
49. AS/HFA shows itself in eccentric behaviours
50. Weaknesses associated with having AS/HFA can be made better by specific types of therapy
51. AS/HFA is a hard condition to live with
52. I do not accept my diagnosis of AS/HFA

APPENDIX 6.1:

Example Q-sorting grid

APPENDIX 6.2:

Copy of conditions of instruction *(Q-sort)*

Statement Sorting Conditions of Instructions – 1.2

I am going to show you a set of **52 statements** about Aspergers Syndrome/High Functioning Autism (AS/HFA). Each statement is a different belief about AS/HFA. All the statements are answers to the broad question, *"What does it mean to have a diagnosis of AS/HFA, when you received the diagnosis as an adult?"*.

The statements have been collected from lots of different sources, including a focus group with people with AS/HFA, current research literature, books written by people with AS/HFA and information on the internet. They represent a range of different beliefs –*they are not facts or the beliefs of the researchers.*

My question to you is *'To what extent do you agree with the following statements?'*. I am going to ask you to rank order these statements from your point of view. I am interested in finding out what having a diagnosis of AS/HFA received in adulthood means to you.

You may agree with some statements but not with others, and you might agree or disagree with statements to different degrees. That is ok. Remember, there are no right or wrong answers. This is not a test.

It is really important to remember before we start that you may find some of these statements upsetting. Remember, you can stop at any point and you can talk to me about any of the statements if you want to, or I can help you find somebody you are comfortable talking to.

Here are the instructions for sorting the statements;

2) Read through all of the 52 statements carefully, and split them up into three piles;
- *Pile one* is for statements you agree with.
- *Pile two* is for statements you disagree with.
- *Pile three* is for statements you neither agree nor disagree with, or that are not relevant or applicable to you.

3) Put the statements you agree with in the box marked AGREE, the statements you disagree with in the box marked DISAGREE; and

the statements you neither agree nor disagree with in the box marked NEUTRAL.

4) Here is a grid for you to place the statements in. The grid has a scale from **+5** for statements you most agree with, down to **-5** for statements you most disagree with.

Under each point on the scale there are spaces, in each space you can put a statement. So for example at +5 you can put two statements and at +4 you can put three statements. All the statements under each scale point have the same rating.

5) From the pile of statements you have selected that you AGREE with, please choose the two statements you **most** agree with. These can go in the three spaces under +5.

6) From the pile of statements you have selected that you DISAGREE with, please choose the two statements you **most** disagree with. These can go in the two spaces under -5.

7) Now, let's go back to the positive pile and choose three statements to go under +4.

8) Now, let's go back to the negative pile and choose three statements to go under -4.

9) Keep going back and forth like this until you have finished the negative and positive piles. Then think about the NEUTRAL pile of statements.

As you are going through selecting your statements, it is ok to change your mind. If you want to swap any statements around then that is ok. You can also review the order you have sorted all the statements in at the end.

APPENDIX 6.3:

Copy of demographic questionnaire *(Q-sort)*

Demographic Interview Form – 1.1

Participant Number: _____

Thank you for completing the statement sort, now I would just like to ask you a few short questions. It is estimated that it will take around 10 minutes to complete. Remember, you do not have to answer any questions you do not want to and you can end the session at any point.

The first questions are about the statements you have just sorted.

1. **Did you sort the statements based on what you believe?** : yes / no

2. **Did you sort the statements based on what others have told you?** : yes / no

3. **Are you satisfied that the way you have sorted the statements reflects what you believe about AS/HFA?** : yes / no

4. **Was there anything difficult about sorting the statements?**

   _____

   _____

   _____

5. **Please can you explain why you *agree most* with the statements that you have placed below +5 ?**

   Statement Number: ……..

   _____

   _____

   Statement Number: ……..

   _____

   _____

6. **Please can you explain why you *disagree most* with the two statements you have placed below -5?**

   Statement Number: ……..

   _____

   _____

Statement Number: ……..

_____

_____

7. Were there any statements you thought should be there and weren't?

_____

_____

_____

8. Were there any statements you thought shouldn't be there?

_____

_____

_____

9. Was there anything else you wanted to say about the statements you have sorted?

_____

_____

_____

Do you have any questions?

The next questions are to find out some information about you which will help me when I interpret how people have sorted the statements. Remember, all the information that you provide me with is completely confidential and anonymous.

1. Date of Birth: _____(day) / _____(month) / _____ (year)

2. Gender: Male / Female

Diagnosis

3. Date of Diagnosis: _____(day) / _____(month) / _____ (year)

4. What diagnosis? : Asperger's Syndrome / High Functioning Autism

5. Where diagnosed (e.g. [redacted], MDT, GP, Private Clinic):

_____

6. What was the motivation for getting a diagnosis? (e.g. self/professional/family):

_____

_____

_____

7. How long did getting a diagnosis take?: _____ (months/years)

8. Were you happy with the diagnosis?: yes / no / not sure

9. a) Did you get any diagnoses prior to the AS/HFA diagnosis?: yes / no

b) What diagnoses?

_____

_____

_____

Mental health difficulties

10. a) Have you had any other mental health difficulties? : yes / no

b) What difficulties? (e.g. depression, anxiety) :

_____

_____

_____

Attainment

11. What level of education did you achieve? (e.g. Standard grades / Highers / Degree) :

_____

_____

_____

12. a) Are you currently employed? : yes / no

b) What job? :

_____

Family

13. Are your family aware of your diagnosis?: yes / no

14. Are you currently in a relationship?: yes / no

15. a) Do you receive support from your family?: yes / no

b) What kind of support? (e.g. practical, emotional)

_____

_____

_____

16. Do any other members of your family have a diagnosis of ASD? : yes / no

17. What is your current living situation? :

Independent living: yes / no

Independent living with support: yes / no

Living within family home: yes / no

Other:

_____

Thank you very much for giving your time and participating.
Do you have any questions?

APPENDIX 6.4:

Copy of GP introductory letter *(Q-sort)*

[redacted]

Private & Confidential

(GP/Consultant address)

Date: [redacted]
Enquiries to: Emma Seel
Email: [redacted]

Dear *(name of GP/Consultant)*,

Re: *(patient name and address)*

My name is Emma Seel and I am a Trainee Clinical Psychologist currently employed by [redacted]. I am carrying out my Doctoral Training in Clinical Psychology at the University of Edinburgh. As part of my training I must complete a piece of clinically relevant research. My academic supervisor for my research is [redacted] in the Section of Clinical & Health Psychology, University of Edinburgh.

What is my research about?
My research project is with people who have been diagnosed with Asperger Syndrome and/or High Functioning Autism in adulthood. It is very likely that following diagnosis different people hold different beliefs about Asperger Syndrome/High Functioning Autism. It is possible that certain beliefs may be associated with better adjustment and mental health. To start to understand these links it is necessary to explore the range of beliefs that are held. It is hoped that the findings of this study will increase this understanding; and provide valuable information for both professionals and people with Asperger Syndrome/High Functioning Autism.

The study involves participants sorting a set of statements based on how much they agree with them. The statements reflect a range of beliefs or assumptions held about the diagnosis of Asperger Syndrome/High Functioning Autism. Additionally a short demographic interview will be completed. Both parts will be completed together, and it is anticipated that in total participation will take 60 minutes. Participants will be asked whether they wish to be involved in an additional feedback stage when they can make comment on the findings.

How can you help?

I am currently working with the [redacted] and I am hoping to recruit people who have been diagnosed by this service. *(Name)* was diagnosed by this service in *(year)*. I note that you are currently responsible for his/her care within NHS *(area)*. I am writing to enquire whether you feel it would be appropriate for me to make contact with *(name)* to briefly introduce the research area. The initial contact would be written and contact details would be provided allowing *(name)* to request further information about participating. If *(name)* decides to participate then written informed consent will be gained. If no response is received then no further contact will be made.

If you feel it would **be appropriate** for me to contact *(name)* regarding my research then please can you complete the attached slip and return it in the stamped addressed envelope provided. I will not make contact with *(name)* unless I receive a fully completed slip.

If you have any questions or queries then I am contactable at the above address, or by telephone on [redacted], or by email on [redacted] .

Yours Sincerely

Emma Seel
Trainee Clinical Psychologist
[redacted]

Please return to Miss Emma Seel (Trainee Clinical Psychologist), [redacted]

Dear Miss Seel,

Please initial box

1) I have read the letter dated …/…./…. and have had the opportunity to ask questions. ☐

2) I agree to ……. ……. *(patients name)* being contacted regarding the research project (A Q-methodological study of beliefs held about AS/HFA). ☐

Name: ……. (Please print)

Relationship to patient: ……..

Signature: …….

Date: ……/……/……

APPENDIX 6.5:

Copy of participant introductory letter *(Q-sort)*

[redacted]

(address of potential participant)

Date: [redacted]
Enquiries to: Emma Seel
Email: [redacted]

Dear *(name of potential participant)*,

My name is Emma Seel and I am a Trainee Clinical Psychologist currently employed by NHS [redacted]. I am currently in the final year of my Doctoral Training in Clinical Psychology at the University of Edinburgh. As part of my training I am carrying out a research project. My academic supervisor for my research is [redacted] in the Section of Clinical & Health Psychology, University of Edinburgh.

My research project is with people who have been diagnosed with Asperger's Syndrome and High Functioning Autism in adulthood. I am currently working with the [redacted] and I understand that you received a diagnosis from them in *(year)*. I have written to your GP *(name of GP/Consultant)* and they have given me permission to contact you about my research project.

What is the research about?
The research is looking at the beliefs people hold about Asperger's Syndrome/High Functioning Autism, when they have received the diagnosis in adulthood (18 +). It is likely that different people hold different beliefs. I hope that the research will increase understanding about the range of beliefs held about Asperger's Syndrome/High Functioning Autism, from the point of view of people who have received the diagnosis.

What would participating involve?
Participating in the research will take 60 minutes and will involve completing two activities;

- Sorting a set of 52 statements about Asperger's Syndrome/High Functioning Autism based on how much you agree with them (approx. 45 minutes).
- Answering a few short questions about yourself e.g. age, date diagnosed (approx. 15 minutes).

We would be able to meet at a time and a place which was convenient for you. Your participation would not affect any medical care or support you were receiving. You would be able to stop participating at any point and this would not affect any care or support you were receiving.

When the research is complete I will be providing feedback to all participants who are happy to receive it and there would be the opportunity to make comments. These comments will be used to produce the final report.

How can I get more information?
This is only a brief introduction to the research. If you would be interested in finding out more information about the research study and participating in it, then you can contact me in a number of ways. I have enclosed a form and a stamped addressed envelope which you can complete. Additionally you can contact me by telephone on [redacted] or by email on [redacted] . I ask you to please contact me within 14 days.

Thank you for taking the time to read my letter, if I do not hear from you then I will make no further contact with you.

Yours Sincerely

Emma Seel
Trainee Clinical Psychologist [redacted]

I **would be** interested in getting more information about this research study. I would be happy for you to contact me.

Please tick the box if you are happy to be contacted

by mail: ☐

by telephone: ☐

by e-mail: ☐

Please complete the following details:

Name: ……
Address: ……
……
……
Postcode: ……
Telephone: ……
E-mail: ……

Signature: ……
Date: ……

Please return this form in the stamped addressed envelope provided to;

APPENDIX 6.6:

Copy of participant information sheet & consent form *(Q-sort)*

PARTICIPANT INFORMATION SHEET – 1.2
Q-sort/Demographic Interview

Title: '*What does it mean to me?': A Q-methodological exploration of the beliefs held about Asperger Syndrome/High Functioning Autism when the diagnosis is received in adulthood.*

You are being invited to take part in a research study that is being carried out by Emma Seel, in part fulfilment of a Doctorate degree in Clinical Psychology at the University of Edinburgh.

Before you decide whether you would like to take part, it is important that you understand why the research is being carried out and what it would involve for you. Please take time to read the following information carefully. Talk to others about the study if you wish.

The information sheet has two parts;

- **Part 1**: This tells you about the purpose of the study and what will happen to you if you take part.
- **Part 2**: This gives you more detail about the conduct of the study.

Please read Part 1 first and then continue onto Part 2.

Please ask questions if anything is unclear or if you would like us to provide more information.

Please take time to decide whether or not you would like to take part.

PART 1 of the information sheet:

The Purpose of the study
This study aims to begin to understand what it *means* to people to receive a diagnosis of Asperger Syndrome/High Functioning Autism as an adult. Different people may hold different beliefs or think different things about having Asperger Syndrome/High Functioning Autism.

A range of individuals diagnosed in adulthood will be invited to participate so we can investigate the range of different meanings that are held by different people.

It is hoped that the study will help professionals who work with people with Asperger Syndrome/High Functioning Autism to better understand what it means to have a diagnosis. The more information professionals have about how people think about their diagnosis, the better able they are to provide the right support.

Why have I been invited?
You are being invited to take part in this study because you are a person who was diagnosed with Asperger Syndrome or High Functioning Autism, or both, during adulthood. We hope to recruit 40-60 people in total.

Do I have to take part?
It is up to you to decide if you want to take part. I (Emma Seel) will describe the study and go through this information sheet with you. I will then give you the information sheet so you can go away and read it again and think about participating.

After no less than 48 hours I will contact you again to ask you if you have made a decision. If you are happy to participate then I will ask you to sign a consent form to show you have agreed to take part.

It is important that you know that you are free to withdraw at any time, without giving a reason. This would not affect the standard of care you receive or your access to any services.

What will happen to me if I take part?
The total length of time it takes to participate is approximately **one hour**.
You will only need to meet with me on one occasion for approximately one hour, the meeting will take place at a location we decide together.

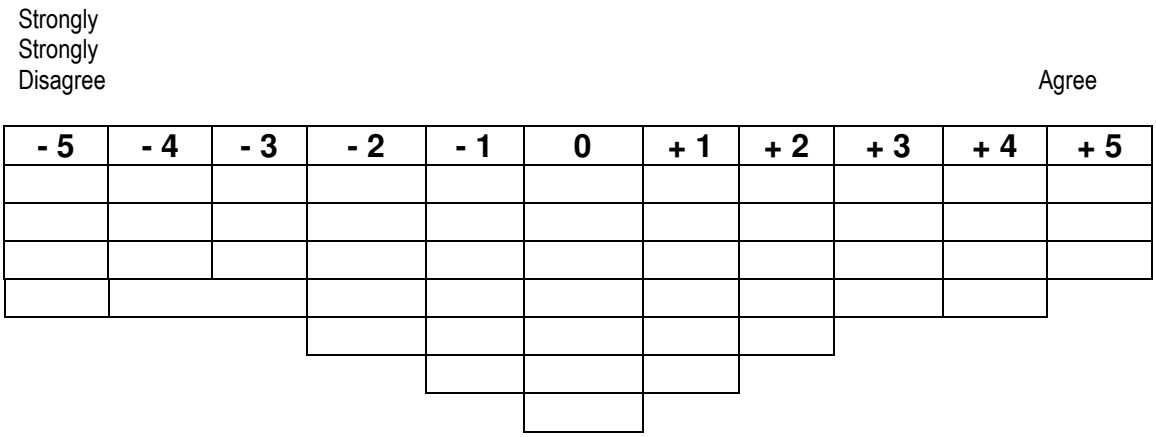
When we meet there will be two tasks to complete.

What tasks do I have to do?	How long will it take?
Sort a set of 52 cards. Each card has one statement about Asperger Syndrome/High Functioning Autism written on it.	Approx. 45 minutes
Answer some questions about yourself (including questions on age, date of diagnosis, education).	Approx. 15 minutes

What will I have to do?
I will be present throughout the duration of your participation and will be available to answer any questions.

At the start of the meeting you will be provided with a set of 52 cards; each card will have a statement relating to Asperger Syndrome/High Functioning Autism written on it. You will be asked to sort these cards into three piles; one pile will be for statements you agree with, another for statements you disagree with and the last pile will be for statements you don't know.

You will then be provided with a grid which will be placed upon the table, the grid will look like the one below.



The grid has a scale from – 5 (strongly disagree) to + 5 (strongly agree) along which you will be asked to sort all of the cards. On the grid there are enough spaces for each of the cards.

While you are sorting the cards you will be provided with a booklet in which all of the statements are written with space for you to make additional comments relating to each statement. I may also write down some of your comments as you complete the task.

At the end of the meeting you will be asked to complete a questionnaire which will include questions about yourself, including asking about your current age, age at diagnosis, relationship status, level of education, profession, any previous or existing mental health difficulties and current living status i.e. living alone. **You do not have to answer any questions you do not want to answer.**

At the end there will be the opportunity for you to ask any questions or discuss anything arising from the task.

At a later date feedback about the findings from the study will be provided. You do not have to participate in the feedback if you do not want to. The feedback will occur in two ways:

- A group feedback session where the findings can be discussed. Participants will have the opportunity to make comments.
- Written feedback of the findings. There will be space for participants to provide comments and a stamped addressed envelope will be provided for the comments to be returned.

You can choose which method of feedback you would prefer. Any comments made will be used to further interpret the findings.

What are the benefits and possible costs of taking part?
Although there may not be any direct benefit for you, it is hoped that the information gained will be used to educate professionals about what it means to receive a diagnosis of Asperger Syndrome/High Functioning Autism as an adult.

Some people may be distressed about thinking about their diagnosis. Some cards may contain statements which people disagree with and find upsetting. It is important to state that these statements are not fact or the beliefs of the researchers but cover a range of potential meanings.

If people are distressed at any point and wish to discontinue participation or have a break that is ok.

What if there is a problem?
Any complaint about the way you have been dealt with during the study or any possible harm you might suffer will be discussed. The detailed information on this is given in Part 2.

Will my taking part be kept confidential?
Yes. We will follow ethical and legal practice and all information about you will be handled in confidence. The details are included in Part 2.

If the information in Part 1 has interested you and you are considering participation, please read the additional information in Part 2 before making any decision.

PART 2 of the information sheet:

What will happen if I don't want to carry on with the study?
You can withdraw from the study at any time.

If you do withdraw then all the data that we have collected from you will be destroyed and will not be included in the final analysis. Withdrawing from the study will not affect any care that you receive from the NHS or any voluntary agency.

What if there is a problem?
If you have a concern about any aspect of this study, you can speak to the main researcher, Emma Seel, either on [redacted] or [redacted] . She will do her best to answer your questions.

If you remain unhappy and you wish to complain formally, you can do this through the NHS Complaints Procedure or through the University of Edinburgh. Details can be obtained from NHS [redacted] or from the Department of Clinical Psychology, University of Edinburgh [redacted].

In the event that something does go wrong and you are harmed during the research and this is due to someone's negligence then you may have grounds for a legal action for compensation against NHS [redacted] or The University of Edinburgh, but you may have to pay your legal costs. The normal National Health Service complaints mechanisms will still be available to you (if appropriate).

Will my part in this study be kept confidential?
We have already said that your participation in the study will be kept confidential and that all the data that is collected from you will not be identifiable. But it is important that you know exactly how this would happen.

What will happen to my data?
The data collected will only be used for this study. Only the main researcher (Emma Seel), the clinical supervisor [redacted] and the academic supervisor [redacted] will have access to the data collected.

Following participation each individual's data will be allocated a number, and will no longer be identified by name. Only the main researcher and the clinical supervisor will have access to the names associated with the specific number. These measures are taken very seriously to protect the anonyminity of the participants.

All data collected will be kept within a locked filing cabinet in NHS property or in a password protected database on an NHS computer. The data collected will be kept for 5 years after the study is completed and then destroyed.

What will happen to the results of the research study?
It is intended that the results of the study will be fed back to the participants directly. This is intended to be done in two ways;

1) The participants will be sent a brief summary report when the research has been completed, there will be space for you to make comments and to return them to the researcher.

2) The participants will be invited to participate in group feedback sessions, where the main results will be presented and offered up for discussion.

Participants can choose which method is best suited to them. There is no requirement to be involved in the feedback sessions or to make comment. Any comments made will be used to further interpret the results.

It is intended that the results of the research will be written up for publication in a journal which is aimed specifically at research into Autism Spectrum Disorders. It is hoped that by doing this that the results will be spread widely in the Autistic Spectrum community and to professionals working in this area.

Participants may make comments which are included in the write up, all of these comments will be anonymous. The feedback of the results, either through publication or by feedback sessions/report, will not include any identifying information. All participants will remain anonymous.

Who is organising and funding the study?
This study is organised jointly between NHS [redacted] and The University of Edinburgh, and will form part of the academic requirements for the main researcher's (Emma Seel) Doctoral training in Clinical Psychology.

Who has reviewed the study?
All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee to protect your safety, rights, wellbeing and dignity. The Fife & Forth Valley Research Ethics Committee, which has responsibility for scrutinising proposals for medical research on humans, has examined this proposal and raised no objections from the point of view of medical ethics.

Who can I contact for more information?
If you require further information about research in general then a useful website is INVOLVE (http://www.invo.org.uk/) which promotes public involvement in the NHS.

If you require further specific information about this research project then please contact the main researcher, Emma Seel at NHS [redacted] . [redacted] (Clinical Supervisor) will also be happy to discuss the research on [redacted] .

If you are unhappy with the study and wish to discuss this with someone then any member of the research team will be happy to discuss this with you. Or please refer to the section on problems during research in Part 2 for more information on the complaints procedure.

Thank you for reading this information sheet and considering taking part in the study.

Location [redacted] *(circle)*

Study: Q-SORT/DEMOGRAPHIC INTERVIEW

Participant Identification Number:

CONSENT FORM – 1.1

Title of Project: What does it mean to me?: A Q-methodological exploration of the beliefs held about Asperger Syndrome/High Functioning Autism when the diagnosis is received in adulthood.

Name of Researcher: Miss Emma Seel

	Please initial
1. I confirm that I have read and understand the information sheet dated ..... (version.....) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	☐
2. I understand that my participation in this RESEARCH is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.	☐
3. I have been informed that only the Chief Investigator (Miss Emma Seel), Academic Supervisor [redacted] and Clinical Supervisor [redacted] will have access to the data collected. At point of participation all data will be anonymised.	☐
4. I agree to take part in the above study.	☐

Additional consent (not required for participation):

5. I am happy to be contacted after participation to receive feedback about the findings from the study, and to comment on the findings. I would prefer this feedback to be written / group session *(please circle)*.	☐
6. I have been made aware that direct quotes may be used in the write up of the research. These quotes will be anonymised. I agree to the use of direct quotes.	☐

_____	_____	_____
Name of Participant	Date	Signature
_____	_____	_____
Name of Person taking consent	Date	Signature

APPENDIX 7.1:

Full rotated factor matrix *(Q-factor analysis)*

Full Rotated Factor Matrix – participants loading significantly on factor (*)

Participants	Factor 1	Factor 2	Factor 3	Factor 4
P1	**0.63***	0.19	-0.13	0.46
P2	**0.54***	0.44	0.36	0.01
P3	**0.78***	-0.20	0.23	-0.14
P4	-0.06	0.06	0.20	**0.74***
P5	0.50	0.52	-0.10	0.38
P6	0.37	**0.63***	0.20	-0.04
P7	**0.83***	0.28	-0.02	-0.00
P8	0.44	0.25	-0.03	**0.61***
P9	-0.06	-0.04	**0.75***	0.32
P10	**0.76***	-0.28	0.07	-0.03
P11	0.15	0.24	**0.83***	-0.16
P12	**0.71***	0.20	0.11	0.33
P13	-0.11	**0.70***	0.20	0.20
P14	0.42	0.11	0.47	0.18
P15	0.16	**0.45***	0.35	-0.09
P16	**0.64***	0.17	0.48	0.09
P17	0.00	**0.78***	-0.07	0.23
P18	-0.01	**0.86***	0.06	0.35

APPENDIX 7.2:

Normalised factor scores *(Q-factor analysis)*

Normalised Factor Scores

Factor 1

No.	Statement	Z-SCORES
11	I would not be me if the AS was not there	1.406
21	Having AS is not my fault	1.359
5	Having a diag. of AS allows me to understand myself better	1.261
14	Having AS is advantageous for some types of work	1.254
8	Having a diag. of AS allows me to move on from past diff.	1.223
20	AS is not caused by upbringing or social circumstances	1.201
25	I'm still likeable & loveable even if I've a diag. of AS	1.172
6	Having a diag. of AS gives answers to previous difficulties	1.117
17	The diff. I have due to AS are dimensions on which all vary	1.045
18	Having AS allows me to come up with ideas nobody else can	0.988
7	Having a diagnosis of AS gives me control over my life	0.921
23	Having AS doesn't mean I'm part of a group of ill people	0.907
13	AS affects people in different ways & to varying degrees	0.820
46	AS is a complicated condition affecting many aspects of life	0.803
50	Weakness. assoc. with AS are made better by specific therapy	0.749
1	Having a diagnosis of AS is a relief	0.734
15	Having AS means there's a diff. in the constr. of your brain	0.686
26	AS will stay with me all through my life	0.650
22	Having AS is a gift	0.608
19	Many diff. people with AS face are due to society not to AS	0.511
16	Having AS is a different way of being in the world	0.459
2	Having a diagnosis of AS is empowering	0.355
10	Having a diagnosis of AS helps me see I'm not alone	0.262
12	I can belong to a community even if I have a diagnosis of AS	0.223
49	AS shows itself in eccentric behaviours	0.182
3	Having a diagnosis of AS is like a new beginning to my life	0.174
4	Having a diagnosis of AS means I am free to be my true self	0.147
39	Living a produc. life with AS is hard work & needs persis.	0.130
33	Having AS means that I do not quite fit in with society	0.074
47	There is nothing I can do to change me having AS	0.009
34	I feel disconnected from other people, because I have AS	-0.006
24	Having AS means that I can access supports and services	-0.074
9	Having a diagnosis of AS helps others understand who I am	-0.153
36	Having AS prevents me from conforming to social expectations	-0.219
51	AS is a hard condition to live with	-0.250
48	AS is a milder form of autism	-0.292
38	I am judged negatively by society because I have AS	-0.325
32	Having a diag. of AS means I'm labelled & stereotyped	-0.455
44	AS is a psychiatric condition	-0.763
41	It is difficult to make friends when you have AS	-0.800
37	I am vicitimised and misunderstood because I have AS	-0.975
35	Society has little use for people with AS	-1.182

30	It is traumatic having AS	-1.190
40	Because I've AS I need exten. support from family & society	-1.306
45	AS is a lifelong disability	-1.417
42	Having AS means I will never achieve as well as my peers	-1.418
28	Having a diagnosis of AS makes me angry	-1.551
31	Having a diagnosis of AS makes me feel confused about myself	-1.572
29	I feel hopeless about having a diagnosis of AS	-1.682
43	AS is an impairment	-1.784
52	I do not accept my diagnosis of AS	-1.974
27	I am ashamed of having a diagnosis of AS	-2.043

Factor 2

No.	Statement	Z-SCORES
45	AS is a lifelong disability	1.951
46	AS is a complicated condition affecting many aspects of life	1.931
26	AS will stay with me all through my life	1.645
34	I feel disconnected from other people, because I have AS	1.606
51	AS is a hard condition to live with	1.603
47	There is nothing I can do to change me having AS	1.453
33	Having AS means that I do not quite fit in with society	1.373
41	It is difficult to make friends when you have AS	1.227
43	AS is an impairment	1.041
30	It is traumatic having AS	1.040
21	Having AS is not my fault	1.036
20	AS is not caused by upbringing or social circumstances	0.938
10	Having a diagnosis of AS helps me see I'm not alone	0.737
5	Having a diag. of AS allows me to understand myself better	0.717
13	AS affects people in different ways & to varying degrees	0.582
40	Because I've AS I need exten. support from family & society	0.376
39	Living a produc. life with AS is hard work & needs persis.	0.278
49	AS shows itself in eccentric behaviours	0.267
15	Having AS means there's a diff. in the constr. of your brain	0.265
11	I would not be me if the AS was not there	0.238
6	Having a diag. of AS gives answers to previous difficulties	0.178
12	I can belong to a community even if I have a diagnosis of AS	0.146
17	The diff. I have due to AS are dimensions on which all vary	0.076
25	I'm still likeable & loveable even if I've a diag. of AS	0.067
48	AS is a milder form of autism	0.052
14	Having AS is advantageous for some types of work	-0.039
42	Having AS means I will never achieve as well as my peers	-0.078
1	Having a diagnosis of AS is a relief	-0.110
37	I am vicitimised and misunderstood because I have AS	-0.192
44	AS is a psychiatric condition	-0.215
16	Having AS is a different way of being in the world	-0.238
38	I am judged negatively by society because I have AS	-0.256
50	Weakness. assoc. with AS are made better by specific therapy	-0.335
18	Having AS allows me to come up with ideas nobody else can	-0.363

32	Having a diag. of AS means I'm labelled & stereotyped	-0.415
24	Having AS means that I can access supports and services	-0.420
8	Having a diag. of AS allows me to move on from past diff.	-0.603
9	Having a diagnosis of AS helps others understand who I am	-0.712
2	Having a diagnosis of AS is empowering	-0.749
23	Having AS doesn't mean I'm part of a group of ill people	-0.752
31	Having a diagnosis of AS makes me feel confused about myself	-0.805
36	Having AS prevents me from conforming to social expectations	-0.813
19	Many diff. people with AS face are due to society not to AS	-0.866
35	Society has little use for people with AS	-1.035
29	I feel hopeless about having a diagnosis of AS	-1.154
4	Having a diagnosis of AS means I am free to be my true self	-1.183
27	I am ashamed of having a diagnosis of AS	-1.264
7	Having a diagnosis of AS gives me control over my life	-1.352
3	Having a diagnosis of AS is like a new beginning to my life	-1.491
28	Having a diagnosis of AS makes me angry	-1.544
22	Having AS is a gift	-1.782
52	I do not accept my diagnosis of AS	-2.057

Factor 3

No.	Statement	Z-SCORES
6	Having a diag. of AS gives answers to previous difficulties	1.870
1	Having a diagnosis of AS is a relief	1.784
5	Having a diag. of AS allows me to understand myself better	1.690
51	AS is a hard condition to live with	1.604
32	Having a diag. of AS means I'm labelled & stereotyped	1.518
31	Having a diagnosis of AS makes me feel confused about myself	1.433
3	Having a diagnosis of AS is like a new beginning to my life	1.433
27	I am ashamed of having a diagnosis of AS	1.243
26	AS will stay with me all through my life	1.072
25	I'm still likeable & loveable even if I've a diag. of AS	0.797
39	Living a produc. life with AS is hard work & needs persis.	0.797
10	Having a diagnosis of AS helps me see I'm not alone	0.626
2	Having a diagnosis of AS is empowering	0.532
34	I feel disconnected from other people, because I have AS	0.455
28	Having a diagnosis of AS makes me angry	0.446
13	AS affects people in different ways & to varying degrees	0.446
46	AS is a complicated condition affecting many aspects of life	0.446
8	Having a diag. of AS allows me to move on from past diff.	0.437
30	It is traumatic having AS	0.361
14	Having AS is advantageous for some types of work	0.361
21	Having AS is not my fault	0.351
11	I would not be me if the AS was not there	0.266
37	I am vicitimised and misunderstood because I have AS	0.180
50	Weakness. assoc. with AS are made better by specific therapy	0.180

36	Having AS prevents me from conforming to social expectations	0.095
12	I can belong to a community even if I have a diagnosis of AS	0.086
45	AS is a lifelong disability	0.086
24	Having AS means that I can access supports and services	0.009
38	I am judged negatively by society because I have AS	-0.171
33	Having AS means that I do not quite fit in with society	-0.180
15	Having AS means there's a diff. in the constr. of your brain	-0.180
20	AS is not caused by upbringing or social circumstances	-0.190
49	AS shows itself in eccentric behaviours	-0.266
16	Having AS is a different way of being in the world	-0.266
17	The diff. I have due to AS are dimensions on which all vary	-0.361
19	Many diff. people with AS face are due to society not to AS	-0.446
41	It is difficult to make friends when you have AS	-0.532
47	There is nothing I can do to change me having AS	-0.541
23	Having AS doesn't mean I'm part of a group of ill people	-0.617
35	Society has little use for people with AS	-0.626
29	I feel hopeless about having a diagnosis of AS	-0.626
18	Having AS allows me to come up with ideas nobody else can	-0.797
48	AS is a milder form of autism	-0.892
9	Having a diagnosis of AS helps others understand who I am	-1.072
40	Because I've AS I need exten. support from family & society	-1.253
7	Having a diagnosis of AS gives me control over my life	-1.338
4	Having a diagnosis of AS means I am free to be my true self	-1.424
52	I do not accept my diagnosis of AS	-1.509
43	AS is an impairment	-1.518
42	Having AS means I will never achieve as well as my peers	-1.604
44	AS is a psychiatric condition	-1.965
22	Having AS is a gift	-2.230

Factor 4

No.	Statement	Z-SCORES
24	Having AS means that I can access supports and services	2.029
19	Many diff. people with AS face are due to society not to AS	1.767
13	AS affects people in different ways & to varying degrees	1.726
50	Weakness. assoc. with AS are made better by specific therapy	1.726
15	Having AS means there's a diff. in the constr. of your brain	1.554
46	AS is a complicated condition affecting many aspects of life	1.423
42	Having AS means I will never achieve as well as my peers	1.342
12	I can belong to a community even if I have a diagnosis of AS	1.293
33	Having AS means that I do not quite fit in with society	1.252
16	Having AS is a different way of being in the world	1.162
14	Having AS is advantageous for some types of work	0.949
41	It is difficult to make friends when you have AS	0.949
34	I feel disconnected from other people, because I have AS	0.736
25	I'm still likeable & loveable even if I've a diag. of AS	0.687
51	AS is a hard condition to live with	0.605
48	AS is a milder form of autism	0.474

1	Having a diagnosis of AS is a relief	0.434
31	Having a diagnosis of AS makes me feel confused about myself	0.434
21	Having AS is not my fault	0.344
9	Having a diagnosis of AS helps others understand who I am	0.303
39	Living a produc. life with AS is hard work & needs persis.	0.041
5	Having a diag. of AS allows me to understand myself better	0.000
3	Having a diagnosis of AS is like a new beginning to my life	-0.041
10	Having a diagnosis of AS helps me see I'm not alone	-0.041
17	The diff. I have due to AS are dimensions on which all vary	-0.131
30	It is traumatic having AS	-0.213
44	AS is a psychiatric condition	-0.213
18	Having AS allows me to come up with ideas nobody else can	-0.221
8	Having a diag. of AS allows me to move on from past diff.	-0.303
52	I do not accept my diagnosis of AS	-0.303
6	Having a diag. of AS gives answers to previous difficulties	-0.344
4	Having a diagnosis of AS means I am free to be my true self	-0.344
23	Having AS doesn't mean I'm part of a group of ill people	-0.434
45	AS is a lifelong disability	-0.434
11	I would not be me if the AS was not there	-0.434
37	I am vicitimised and misunderstood because I have AS	-0.474
28	Having a diagnosis of AS makes me angry	-0.515
40	Because I've AS I need exten. support from family & society	-0.646
43	AS is an impairment	-0.687
26	AS will stay with me all through my life	-0.736
7	Having a diagnosis of AS gives me control over my life	-0.777
2	Having a diagnosis of AS is empowering	-0.859
20	AS is not caused by upbringing or social circumstances	-0.908
36	Having AS prevents me from conforming to social expectations	-0.949
27	I am ashamed of having a diagnosis of AS	-0.990
47	There is nothing I can do to change me having AS	-1.039
49	AS shows itself in eccentric behaviours	-1.211
32	Having a diag. of AS means I'm labelled & stereotyped	-1.211
29	I feel hopeless about having a diagnosis of AS	-1.423
22	Having AS is a gift	-1.464
38	I am judged negatively by society because I have AS	-1.685
35	Society has little use for people with AS	-2.201

APPENDIX 7.3:

Best-estimate Q-sorts for each factor

FACTOR 1

Most disagree									Most agree	
- 5	**- 4**	**- 3**	**- 2**	**- 1**	**0**	**+ 1**	**+ 2**	**+ 3**	**+ 4**	**+ 5**
27*	**31***	40	32	34	10	1	**18***	20	5	**11***
52	29	**45***	44	24	12	15	**7***	25	14	21
	43	42	41	9	49	26	**23***	**6***	**8***	
		28	37	36	3	**22***	13	**17***		
			35	**51***	4	**19***	46			
			30*	48	39	16	50			
				38	33	2				
					47					

FACTOR 2

Most disagree									Most agree	
- 5	**- 4**	**- 3**	**- 2**	**- 1**	**0**	**+ 1**	**+ 2**	**+ 3**	**+ 4**	**+ 5**
22	7	35	9	16	17	**40***	30	**47***	26	**45***
52	**3***	29	2	38	25	39	21	33	**34***	46
	28	4	23	50	48	49	20	41	51	
		27	**31***	18	14	15	10	**43***		
			36	32	**42***	11	5			
			19	24	1	6	13			
				8	37	12				
					44					

FACTOR 3

Most disagree									Most agree	
- 5	**- 4**	**- 3**	**- 2**	**- 1**	**0**	**+ 1**	**+ 2**	**+ 3**	**+ 4**	**+ 5**
44*	52	9	47	15	37	13	25	**31***	5	**6***
22	43	40	23	2	50	46	39	**3***	51	**1***
	42	7	35	49	36	8	10	**27***	**32***	
		4	29	16	12	30	2	26		
			18	17	45	14	34			
			48	19	24	21	**28***			
				41	38	11				
					33					

FACTOR 4

Most disagree									Most agree	
- 5	**- 4**	**- 3**	**- 2**	**- 1**	**0**	**+ 1**	**+ 2**	**+ 3**	**+ 4**	**+ 5**
38*	**32***	36	40	6	3	48	16	46	**13***	**24***
35*	29	27	43	4	10	1	14	**42***	**50***	**19***
	22	47	**26***	23	17	**31***	41	**12***	**15***	
		49*	7	45	30	21	34	33		
			2	11	44	9	25			
			20	37	18	39	**51***			
				28*	8	5				
					52*					